

**Developing and testing a community-based nursing intervention to improve engagement of HIV Patients in care and treatment (Conect) (Abstract only)**

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# Alternative, Oral, Poster and Symposia Abstracts for QHR, 2019

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## 2019 QHR Conference Vancouver - Canada



### Alternative Presentations—Micro Orals and “Golden Nuggets”

#### **Soldiers’ Stories: Themes of Collective Healing and Recovery in a Group Treatment for Trauma in Military Veterans**

Alisha Ali, *New York University*

Stephan Wolfert, *DE-CRUIT Veterans Program*

Ruby Smith, *New York University*

Jessica Healy, *Brooklyn College, City University of New York*

The DE-CRUIT Program is an 8-week manualized group treatment for trauma in military veterans that integrates narrative therapy and routinized techniques of theatre and classical actor training (e.g., grounding, breathing, and the experiential analysis of verse). The core of the program is Shakespeare. Participants examine the many soldier and veteran characters in Shakespeare’s plays and see the timelessness of veterans’ suffering through these texts from centuries ago. After immersing themselves in the Shakespearian monologue form, the veterans each write a firsthand trauma monologue which they hand off to a fellow veteran in the group who performs it, thereby providing the aesthetic distance they need for processing their self-blame at causing injury and death. They ultimately perform their monologues for an invited audience of family, friends, and other civilians as a way of sharing their healing with the broader community. While our quantitative analyses of the

program’s treatment outcomes show significant improvements in symptoms of post-traumatic stress and depression, we know far less about the inner therapeutic experience that the veterans go through in the program. For insight into that experience, we conducted a thematic analysis of the monologues written by 19 veterans in the program. Findings revealed two prevalent themes: (a) the therapeutic effects of the group camaraderie and communalization of trauma, and (b) the benefits of using the self-regulatory techniques of grounding and breathing in their day-to-day lives. These findings have been crucial in the further development and refinement of the program to serve more veterans

#### **Health Care Providers Have a Role to Play in Supporting the Transition to Higher Education for Youth With Sickle Cell Disease: Youth and Staff Perspectives**

Brooke Allemang, *Faculty of Social Work, University of Calgary*

Rosemary Leone, *Haematology Clinic, Hospital for Sick Children*

James Bradley, *Haematology Clinic, Hospital for Sick Children*

The transition from high school to postsecondary education is challenging for youth with sickle cell disease (SCD) who experience multiple life transitions simultaneously. Although postsecondary institutions offer support to address the impact of chronic health conditions like SCD on



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academic performance, literature exploring how youth access and utilize these services is scant. In order to promote postsecondary success for patients with SCD, a quality improvement initiative was undertaken in an outpatient hematology clinic at a pediatric hospital in Ontario. A series of handouts about relevant accommodations and financial support were distributed to all patients ages 17–18 with SCD from January 2017 to July 2018. Patients also received support in registering with postsecondary accessibility offices and applying for financial assistance from hospital staff. Semistructured interviews were then conducted with postsecondary accessibility office staff and patients to obtain their perceptions of the handouts and their experiences. Thirteen accessibility office staff from Ontario colleges/universities and 10 youth with sickle cell disease who had completed at least 1 year of postsecondary education were interviewed. Thematic analysis was used to identify key themes across the staff and patient interviews. Patients and staff endorsed the importance of informing youth with chronic conditions about postsecondary supports in the health care system and bolstering self-advocacy skills. Barriers and facilitators to successful transition to higher education for youth with sickle cell disease were identified. Clinical implications for health care providers working with youth with chronic health conditions will be shared.

### **A Two-Eyed Seeing Approach to Wholistic Healing and Wellness for People With Drug Use Experience**

Kehinde Ameteppee, *Simon Fraser University*

Matthew Fischer, *Indigenous Wellness Research Group*

Candice Norris, *Indigenous Wellness Research Group*

Alexandra King, *University of Saskatchewan*

Substance use is typically through an individualistic framework, where current health status results from poor lifestyle choices. However, an Indigenous health determinants framework, which emphasizes structural and sociocultural impacts on health, better explains Indigenous overrepresentation in substance use and related conditions. Land-based retreats have been used for wholistic wellness and being explored for their effectiveness in promoting healing in the context of substance use. Land- and culture-based retreats which included the Medicine Wheel Spirit Shadow Dance (MWSSD)—a wholistic, strengths-based approach developed by people living with HIV and substance use experience to promote self-exploration and healing based on medicine wheel teachings—along with post-retreat activities were designed with contextualization by Knowledge Holders for their specific communities. This was piloted in two sites—a First Nation community in Saskatchewan and an urban Indigenous community in British Columbia. A two-eyed seeing multipronged evaluation included a qualitative analysis of intra- and postretreat sharing circles, self-

reflexivity, and an innovative First Nation self-assessment tool. Findings identified elements of land- and culture-based healing effective at restoring and promoting wellness for Indigenous people who use drugs. The MWSSD provides a shame-free space for sharing of and both individual and collective learning from deeply personal narratives. Culture offers a promising path towards wholistic wellness for Indigenous communities impacted by HCV, HIV, and substance use. Yet, despite the demonstrated need, challenges regarding funding remain. Given the extent of health inequities faced by these communities, it is imperative that these gaps in research and services are promptly addressed.

### **Meaningful Treatment Outcomes for Sanfilippo Syndrome: Using a Combination of Focus Groups and Best–Worst Scaling to Elicit and Explore Parents’ Priorities**

Sara Andrews, *RTI International*

Carol Mansfield, *RTI Health Solutions*

Cara O’Neill, *Cure Sanfilippo Foundation*

Holly Peay, *RTI International*

Sanfilippo syndrome (MPS III) is a pediatric-onset, fatal lysosomal storage disorder with no approved therapies. We conducted a mixed method study exploring parent perceptions of MPS III symptoms with greatest impact and meaningful benefits that could be obtained from a noncurative therapy. Using an innovative approach with 25 parents of children with MPS III, we conducted three focus groups comprising two activities: (#1) a moderated exploration of burden and meaningful treatment benefit and (#2) a best–worst scaling (BWS) preference elicitation to quantify the relative importance of benefits that arose during activity #1. BWS Case 1 is an approach to prioritization where respondents choose features that are most and least important to them (in this case, MPS symptoms that parents reported during the focus group) in a series of questions. The balanced, incomplete block design was preset for 12 prioritization sets, each with five features. Investigators entered features in real time and then participants selected the most and least important in each set. Quantitative BWS analysis yielded utility scores from most to least important. Though BWS items varied somewhat across focus groups, the domains and prioritization results were similar. The synergistic combination of moderated discussion and BWS facilitated additional discussion among participants. The BWS results then augmented thematic analysis of qualitative data. A combination of qualitative data and customized BWS conducted in “real time” during focus groups is a novel and effective way to elicit nuanced, actionable data—in this case, about meaningful outcomes in the treatment of rare disease.

## **Engaging Communities in Monitoring Local Food Environments: Experiences of Stakeholders**

Breanne Aylward, *School of Public Health, University of Alberta*

Krista Milford, *School of Public Health, University of Alberta*

Kim Raine, *School of Public Health, University of Alberta*

Children are increasingly exposed to food environments that have negative impacts on their diet and health. Evidence supports the use of interventions that involve whole communities, use multi-level strategies, and consider multiple settings to promote healthy eating. However, there is insufficient evidence addressing how to best implement such community-based interventions. Because local stakeholders are key players in creating and implementing self-sustaining community-based interventions, understanding their experiences may provide implementation insights. Local Environment Action on Food (“LEAF”) aims to stimulate local action in changing food environments by engaging stakeholders in collecting local data and developing context-specific recommendations. This research aims to assess if and how LEAF facilitates the creation of local food environments that support healthy eating. A qualitative collective case study design using semistructured interviews with a purposeful sample of approximately 25 stakeholders explores LEAF stakeholder experiences of collecting food environment data and creating change. Document analysis aids in contextualization of interview data. Data collection and analysis are iterative, following Stake’s phases of direct interpretation, categorical aggregation, correspondence and patterns, and naturalistic generalizations. Preliminary findings suggest that integrating local knowledge and working across sectors to create recommendations for action on food environments produces a context-specific tool to ask for changes at the local level. Engaging local stakeholders in monitoring food environments can promote local action to improve food environments that promote healthy eating. As such, local stakeholders can build capacity for the development of sustainable public health interventions.

## **As a Native Person in Canada, You Have to Learn How to Be Strong—It’s Innate in Us to Cope: Indigenous Perspectives on Health and Resilience Following a Wildfire Disaster**

Tara Azimi, *University of Alberta*

Kayla Fitzpatrick, *University of Alberta*

Stephanie Montesanti, *University of Alberta*

Métis and First Nations peoples living in urban and rural communities in Northern Alberta were devastatingly impacted by the 2016 Horse River wildfire. The Indigenous Health and

Resilience through Disaster (IHRD) led by researchers at the University of Alberta, in partnership with Indigenous organizations, came together to understand how the health of Indigenous residents and communities were impacted by the wildfire. Sharing circles were organized with Indigenous Elders, adults and youth living in urban and rural communities to capture: (1) Indigenous interpretations of resilience (i.e., what helped them to cope during and after the wildfire), (2) individual- and community-level factors of Indigenous resilience during and after the wildfire, and (3) intergenerational experiences of resilience. The number of participants in each sharing circle ranged from 8 to 12 people. Findings from the sharing circles highlighted the importance of social media during the evacuation as a source of information about the fire and for connecting with loved ones who were displaced; the factors affecting the ability of Indigenous residents to cope during and after the wildfire such as stress from the confusion of the evacuation, feelings of being forgotten, unequal or lack of services and supports, and feelings of loss; and lastly community and social enablers of resilience which included supports from social networks, bonding through shared experiences, spirituality, faith, and gratitude. The findings from this research shows the value of Indigenous perspectives on resilience for future preparation, response, and recovery from a natural disaster.

## **Insights About Perceptions of Health, Identity, and Community Through Comparing Visual Art Practices in Physical and Online Settings**

Cindy Brooks, *University of Southampton*

Catherine Brigitte Matheson-Monnet, *University of Southampton*

Engagement in artistic and creative practices (such as painting, crafts or music) is gaining increasing recognition, for its potential to enhance people’s health and identity, as well as promoting a sense of belonging to a community. Pivotal to this potential is the extent to which artistic practices are available, accessible, and inclusive. This presentation reports on early findings from a comparative study of perceptions of health, identity, and community through sharing artwork online or through participation in a regular art activity in a public setting in the South of England. The aim of the study is to gain insights into how concepts of health, identity, and community are conceptualised in these two settings by using an ethnographic approach involving observations, focus groups, and interviews, including an auto-ethnographic approach by the principal researcher (who is herself an artist) to report upon her reflections. It is anticipated that findings will show areas of synthesis and divergence between online and physical participation in visual art practices, for example, local and international conceptualisations of community. In addition to conceptual and methodological insights, findings may shed light on the relational and contextual features that impact on the development

and sustenance of artistic practices at a local and international level and the extent to which these contribute to fostering a sense of health, identity, and community.

### **Pharmacist-Led Workplace Wellness Program in Western Canada: A Qualitative Study**

Annalijn Conklin, *University of British Columbia*

Anita I Kapanen, *University of British Columbia*

Barbara Gobis, *University of British Columbia*

Larry Leung, *University of British Columbia*

Preventing cardiovascular diseases (CVD) is a public health and policy priority, and workplace CVD prevention could benefit employed populations. A novel CVD screening program that included medication management was delivered by pharmacists to employees of a Canadian university. Understanding participants' perspectives is important for program improvement. We report on the perceptions and experiences of participants who received individual health consultations in this program using qualitative data from an evaluation. We used grounded theory techniques to thematically analyse written responses to four open-ended questions from the evaluation survey completed by 119 participants after their final visit (between October 2016 and October 2017). We validated codes and themes in a focus group of pharmacists and interviews with selected participants. Analysis revealed that personalised health information and advice on CVD risk factor management empowered many participants to improve their health who might not otherwise have done so. Participants expressed a range of positive responses about the extended duration, supportive communication, and safe setting of their pharmacist consultations. Combined, these factors helped improve participant perceived self-efficacy in CVD risk factor management. A number of changes to behaviour and health measures were identified and participants' suggestions to expand and continue the program further contributed to positive perceptions of program impact. This study raises questions about how external resources and broader determinants act as enablers of, or barriers to, program success and sustainability. It also highlights the need for greater understanding and public discourse on the role of pharmacists in primary CVD prevention and health promotion.

### **Optimizing Abdominal Surgery: Patient Experiences and Preferences for Preoperative Care**

Annalijn I. Conklin, *University of British Columbia*

Rebecca Wang, *University of British Columbia*

Christopher Yao, *University of British Columbia*

Logan Meyers, *University of British Columbia*

Colorectal cancer and other gastrointestinal conditions affect almost a third of Canadians, and the burden of colorectal cancer

is rising globally. Surgery is a major treatment but has high morbidity and so a new concept of "prehabilitation" is being proposed to help improve patient outcomes. There is very known about patient experiences during the preoperative period which is important to inform planning and delivery of preventive care before surgery. The current study used focus group methodology to explore patient experiences of preoperative self-care support and their perspectives on a structured approach for patient self-care to help optimise health before surgery. Qualitative data from three focus groups were transcribed verbatim and coded inductively to support data analysis. Five themes were generated and showed the interconnectedness between physical and mental health, emphasizing the need for mental health support that patients felt was more important but typically neglected. All themes tied into mental health and also to informed decision-making as central themes in the patient preoperative experience. Future prehabilitation programming should focus on providing patients with clarity on the benefits of prehabilitation for their outcomes and with enough information about their options for self-management support to make their own decisions about the support they want.

### **Insights to Support Patient Engagement Research With Medically Fragile Young Adults**

Karen Cook, *Athabasca University*

Joanie Maynard, *Athabasca University*

Kim Bergeron, *Athabasca University*

Patient engagement research focuses on priorities that are important to patients with an emphasis on producing results that improve their health care experiences, health outcomes, and health care funding. This type of research requires collaboration among patients, their families, researchers, and health care providers to create meaningful outcomes for patients and build sustainable programs. Our presentation focuses on our innovations to engage a hard to reach population of medically fragile young adults to determine what could be done to improve services and opportunities for them to achieve their goals within their shortened lives. The insights we will highlight are:

1. Sensitive recruitment strategies.
2. Options available for study participants to choose their level of involvement based on their health and energy.
3. The attributes of Group Concept Mapping which facilitate and support the principles of patient engagement.

### **A Phenomenological Hermeneutic Approach on Public Health Nursing Work**

Berit Misund Dahl, *NTNU-Norwegian University of Science and Technology*

The aim of this study was to explore Norwegian public health nurses' experiences with population-based work. The study has a

phenomenological hermeneutic approach, inspired by the philosophy of Ricoeur and adapted as a research method within health care by Lindseth and Nordberg. The method is suitable for revealing in-depth knowledge. Semistructured face-to-face interviews with a narrative approach were performed to illuminate the practical experiences of the nurses. Stories from practice can reflect public health nursing strategies and challenges. The analyzing method involved three steps: a naive reading of the transcribed text, resulting in a naive understanding; a structural analysis, revealing themes; and a critical reading, leading to a comprehensive understanding of the text. The analysis was a dialectic movement between an explanation and a naive and comprehensive understanding. The emphasis was on what the transcribed text illuminated about possibilities of living and acting as a professional, that is, the interviewed public health nurses' experiences with population work. Ricoeur maintained that the interpretation process can reveal many truths, but some interpretations are more probable than others. Rich descriptions and variations in the interview text required a strict interpretation process, where internal consistency and possible other interpretations were taken into consideration. Representative quotations from the interviewees are provided in the findings section to illustrate similarities and differences in the transcribed text. The findings must be interpreted in this context and therefore cannot be generalized. However, the findings can be transferred to similar contexts and viewed as arguments in an ongoing discourse.

### **A Gender Perspective on How Household, Social, and School Environments Affect Student Nutritional Behaviours as They Transition to Secondary School**

Alysha Deslippe, *University of British Columbia*

Tomoko McGaughey, *University of British Columbia*

Louise Masse, *University of British Columbia*

Dietary behaviours affect the risk of childhood obesity. Importantly, youth's dietary behaviours deteriorate during the transition to secondary school. This qualitative analysis used a gendered lens to examine individual and environment factors (namely, household, social, and school environments) that influence youth's dietary behaviours as they transition into secondary school. Twenty-eight semistructured family interviews (parent-child dyads [11–13 years]) were conducted with a diverse sample from Surrey, BC. Interviewers probed for changes in youth's environments that may have effected their dietary behaviours. Using NVivo Version 12, thematic analysis explored differences among boys and girls and the effect of parent gender.

Preliminary analyses suggested diversity among boys and girls including: healthy eating motivation (boys-direct parental influences vs. girls-indirect parental influences), eating out rationale (boys-convenience vs. girls-socialization), autonomy in dietary behaviours (boys-preferences vs. girls-food

preparation), meal skipping (boys-internal factors vs. girls-external factors), peer influences (boys-new food introduction vs. girls-junk food consumption), and lunch time priority (boys-satiety/sports vs. girls-socialization). Boys and girls also had different views of mothers' (primary) and fathers' (secondary) role in food-related tasks. For parents, three gendered themes emerged including: feeding beliefs (fathers-quantity vs. mothers-quality), expectations of teens (boys-eat what's prepared vs. girls-help prepare food), and availability of junk/fast foods (fathers-personal preference vs. mothers-teen preference).

These findings highlight the need to acknowledge how gender influence youth's perceptions and experiences with food as they transition to secondary school. Such consideration may inform programming to support healthy eating among boys and girls, helping reduce the health risks associated with poor dietary choices at this age.

### **Innovative Methods in Qualitative Health Research: Thinking With Postqualitative Inquiry and Feminist New Materialism in Qualitative Health Research**

Emilie Dionne, *McGill University & St. Mary's Research Centre*

Postqualitative inquiry (PQI) is an emerging field in qualitative research (QR). Qualitative researchers experiencing frustration with approaches to methods in standard, traditional QR argue for the need to think anew QR, notably its approach to methods (i.e., rigid, "ready-to-apply" recipes/frameworks). Resituating traditional QR in its history, PQI shows how all research methods are situated, tied to a context and a history, meaning that methods are designed as an answer to particular problems tied to a space-time-matter moment. Transposing to other contexts and times, methods raise issues and concerns, notably ethical ones, for example, What are the effects of applying methods designed for another paradigm and to answer a historically and culturally situated question, to another time and problem? Are these methods effective? Are they the appropriate design to study contemporary issues? What could be the consequences, some material; others, epistemological; some, ethical? PQI argues for the need to "go back" to theory for appropriate, relevant, and ethical research and to echo new/emerging directions in philosophy and social and political thought. Whereas traditional, liberal-humanist, QR relies on philosophical contributions such as hermeneutics, phenomenology, and Freudian psychology, PQI works with poststructuralist philosophies such as the "new" materialist and new empiricist approaches. While burgeoning, PQI remains marginal in Qualitative Health Research. Working with the literature, this article documents some of the reasons why PQI remains challenging for health research, explores the relevance and importance of PQI to Qualitative Health Research, and presents examples of PQI projects in health research.

## Complementary Sampling Methods in Recruiting Participants for Qualitative Health Research

Sinegugu Duma, *University of KwaZulu-Natal*

**Background:** Students and novice qualitative health researchers often experience difficulties when they want to investigate how different participants respond differently to a similar health issue or phenomenon such as recovery from rape. Purposive sampling has become a sampling method of choice for most qualitative health researchers, but there are other complementary sampling methods that can be used to understand and explain how different people respond differently to the similar phenomenon. **Nature of Issue:** The purpose of the study was to determine and describe the factors that influence the journey of recovery from rape among women in South Africa. The central criterion for participation in the study was having experienced rape within the first week of being approached for recruitment. The principle of literal replication and the principle of using polar cases, common in theoretical sampling, were used to complement purposive sampling. This assisted the researcher to identify how women who had family support or lacked family support (principle of replication); women who have been raped by intimate partner and those who were raped in their own houses (principle of using polar cases) all influenced the women's journey of recovery from rape. **Learning Issue:** Sharing the complementary sampling methods with students and novice qualitative researchers has helped them in strengthening their sampling and recruitment strategies. Understanding and accurately applying these complementary sampling methods in qualitative health proposals have since reduced the amount of proposals which were rejected or returned by the Research Ethics Committees for further clarification of sampling and recruitment methods.

## Food and Nutrition Influencers Are Mainly Self-Taught Cooks and Self-Proclaimed Health Experts

Melissa Fernandez, *University of Alberta*

Sophie Desroches, *Institute of Nutrition and Functional Foods, School of Nutrition, Université Laval*

Kim D. Raine, *School of Public Health, University of Alberta*

Instagram influencers exploit their social capital to promote products, services, and ideas to the public. They can reach the masses to influence the eating practices of the public through their extensive following. Yet, little is known about who they are or the content that they share. The purpose of this study is to characterize profiles of food and nutrition Instagram influencers. Influencers were identified with key word searches (e.g., nutrition influencers) in Google, Yahoo!, and Bing. Profiles of

124 food and nutrition influencers with publicly accessible and active webpages and Instagram accounts and at least 15k followers were selected for analysis. The “about” section, products, and services from webpages were copied into a template and imported into NVivo. Based on the initial analysis of 10 divergent influencers, a codebook was built organically through inductive coding using a thematic network analysis approach. The global theme that emerged was “food and nutrition (mis)information” and three key organizing themes “ideology,” “communication,” and “experience” were identified. Experience from self-taught food practices and self-proclaimed health expertise propels influencers towards becoming social media entrepreneurs. Personal ideologies about the health properties of food and the virtues of cooking are integrated into social media content. Influencers sell products, services and provide free resources, mainly recipes. The fact that sharing food and nutrition information is driven by entrepreneurial enterprises that sell products and services grounded in personal ideologies casts doubts about the quality of content created. Future research should assess the quality of content shared by Instagram influencers.

## The Experience and Values of Using Codebooks for Qualitative Team-Based Research: Two Practical Examples

Dailys Garcia-Jorda, *W2IC Research and Innovation Centre, University of Calgary*

Caillie Pritchard, *Cumming School of Medicine, University of Calgary*

Sarah MacDonald, *Cumming School of Medicine, University of Calgary*

Team-based research for qualitative studies may be challenging due to variability in experience and skills of researchers as well as staff renewal rate. Developing comprehensive codebooks helps to ensure the trustworthiness of the reported data and improves the ability of a team to analyze large data sets in a precise and consistent manner. Through practical examples, we report our experience developing comprehensive codebooks for two studies: “Connect to Care (C2C), a novel community outreach program for socially vulnerable patients with complex needs” and “the ENCOMPASS Study—Enhancing COMMunity health through Patient navigation, Advocacy, and Social Support.” In both studies, one researcher experienced in qualitative methods developed an original codebook, which consisted of code names, their definitions, inclusion and exclusion criteria, and examples. For the first study (C2C), inductive thematic analysis was used to analyze a sample of transcripts to develop the codebook that guided further coding by multiple researchers. For the latter, the codebook was developed using all data collected from a pilot phase of the study to inform the qualitative component of a subsequent mixed method trial. The methodological approach combined theory-driven codes drawn from a program theory and data-driven coding. In both studies,

before expanding the coding and frequently thereafter, the team systematically evaluated the utility of the codes, their ability to apply the codebook consistently, and incorporated emerging data. Developing codebooks for qualitative studies provided a structure for analyzing data and training researchers that was flexible enough to meet the needs of different studies and research questions.

### **The Role of Community Health Navigators in Addressing Sources of Health Care Disparities: A Qualitative Study of the ENCOMPASS Navigation Program**

Dailys Garcia-Jorda, *W2IC Research and Innovation Centre, University of Calgary*

Kerry A. McBrien, *Cumming School of Medicine, University of Calgary*

David J. T. Campbell, *Cumming School of Medicine, University of Calgary*

The ENhancing COMMunity health through Patient navigation, Advocacy and Social Support (ENCOMPASS) study is evaluating a community health navigator (CHN) intervention for adults with multiple chronic conditions in Calgary, Alberta. As part of a pilot evaluation, we conducted semistructured interviews and observations to obtain a better understanding of the experiences and perceptions of the program from the perspectives of patients, clinical providers, and health navigators. A total of 16 individuals participated in the study: two program managers, five patients, five health care providers (two nurses and three family physicians), and four CHNs were interviewed. CHNs were also observed while working with patients or meeting with the team. Data were analyzed using thematic analysis. Common sources of health care disparities addressed included financial, transportation, and language barriers, isolation, food insecurity, and lack of knowledge or ability to navigate the fragmented health system. Our findings show that CHNs adapt their management plan based on patient needs, the complexity of their circumstances (either medical or social), and the support they have or lack. This study highlights the importance of navigation services to address barriers to care by elucidating the ability of health navigators to connect with patients and recognize barriers that may go unrecognized by other healthcare providers.

### **Service Provider Perspectives on the Mental Health and Well-Being of Newcomer Young Men in Canada**

Carla Hilario, *University of Alberta*

Bukola Salami, *University of Alberta*

Josephine Pui-Hing Wong, *Ryerson University*

Addressing the well-being and mental health care needs of vulnerable immigrant and refugee young men is increasingly

recognized as a key determinant of their successful integration in Canada. This micro oral presentation presents initial findings from a research study aimed at engaging service providers in identifying and addressing the mental health needs of newcomer young men in Canada. Focus groups and individual interviews were conducted with service providers and program managers connected to immigrant-serving organizations in three sites in Alberta and British Columbia. Thematic analysis was used to examine the transcribed audio-recorded data for key themes in relation to the challenges and opportunities in providing service to this group. We drew on the framework of intersectionality to explore service providers' perspectives on how newcomer young men's multiple social identities and positions shape their mental health and mental health care needs. The presentation will highlight key themes from the study and explore how the findings can contribute to informing mental health care for immigrant and refugee young men.

### **"I Constantly Worry That It Is Going to Drive A Wedge . . . and Cause Our Marriage to Fail": A Qualitative Exploration of Perspectives on How Gynecologic Cancer Impacts Romantic Relationships**

Madison Lyleroeher, *Northwestern University*

Sally Jensen, *Northwestern University*

Allison Fisher, *Northwestern University*

Sara Shaunfield, *Northwestern University*

Individuals diagnosed and treated for gynecological cancers (GC) experience changes in various aspects of their lives, including their romantic relationships. While researchers suggest that physicians should provide resources to GC patients and their partners for coping with impacts to their relationships, it is unclear what specific concerns should be addressed. To explore relational effects important to GC patients, we conducted a secondary analysis of data collected to develop a sexual health impacts questionnaire, which consisted of 44 interviews with individuals formerly and currently diagnosed with GC. Analysis for the present study focused on in-depth discussions of relational concerns and impacts related to GC. Interview transcripts were inductively analyzed using a constant comparative approach. Coding was performed in Dedoose by four analysts, and the text for each code was subsequently extracted, reviewed, and collapsed into larger themes through team discussion. Three themes regarding relational impacts of GC emerged from the data including sexual activity concerns, partner communication, and romantic perspectives. Specifically, participants described experiencing concern over reduced sexual activity and resulting relational harm. Concerns over partner communication involved reduced quality and quantity, and for single participants, anticipated concerns over communication with future partners. Finally, participants experienced changes in their perspectives on relationships, both romantic and sexual. The results of this



study can help inform clinical and psychosocial support teams of the relational concerns that are important to address with individuals diagnosed with GC and their partners before, during, and after GC treatment.

### **Beyond the Yuck Factor: Faecal Microbiota (Stool) Transplantation for Ulcerative Colitis—A Qualitative Study**

Jonathan Mathers, *Institute of Applied Health Research, University of Birmingham*

Tariq Iqbal, Professor, *University Hospitals Birmingham*

Christel McMullan, *Institute of Applied Health Research, University of Birmingham*

Faecal microbiota transplantation (FMT), or stool transplantation, is a novel treatment for ulcerative colitis (UC), a chronic relapse remitting form of inflammatory bowel disease for which current medical therapies are not always effective. FMT, as a donation of “healthy bacteria” aims to influence the gut microbiome in order to treat UC. It is an established treatment for resistant *Clostridium difficile* infection, but not yet routinely available to patients with UC. We have conducted qualitative research with patients ( $n = 32$ ) and staff ( $n = 11$ ) participating in a UK-based pilot RCT of FMT for the treatment of UC. Patients were randomly allocated to receive FMT via a nasogastric or colonic route. Interviews with patients at two points in this pilot trial have explored their views regarding FMT as a treatment for UC, their motivation to take part in the trial, their preferences regarding route of administration, and their experience of the treatment and its effects. Staff have also discussed their experience of working with FMT and administering stool transplants. Data were analysed using thematic approaches informed by Framework. This qualitative research is a core part of the assessment of whether to proceed beyond the pilot phase of the trial and which route of transplantation would be taken forward to a main RCT. In this presentation, we consider initial insights from this qualitative data and their implications for FMT as a treatment for UC.

### **SocialTech ASD Knowledge Translation (KT) Initiative: Parents’ and Clinicians’ Perspectives on Using Technology to Promote Social Skills of Children With Autism**

Yael Mayer, *The University of British Columbia*

Tal Jarus, *The University of British Columbia*

Parisa Ghanouni, *The University of British Columbia; Dalhousie University*

Ally Malinowski, *The University of British Columbia*

It has been widely reported that many children with autism spectrum disorder (ASD) have an affinity for computers and

video games. This affinity can be a benefit since technology can help the development of social skills of children with autism. However, finding systematic knowledge of useful technology to promote life and social skills of children with autism can be difficult. In this article, we will present a KT initiative named SocialTech ASD to promote parents’ and clinicians’ knowledge on ways that children with ASD can benefit from the use of technology. Using the knowledge to action process framework, we created KT materials aimed at enhancing the knowledge of stakeholders on this topic. To evaluate the impact of our KT strategy, we used a mixed methods approach, including surveys and focus groups and interviews with participants. Within this article, we will present the KT materials and interventions, the methodology used to evaluate its effectiveness, and the preliminary findings from this study.

### **Understanding the Lived Experiences of Women Aged 60–75 With No Children Due to Life Circumstances in Sydney, Australia**

Naomi Menahem, *La Trobe University*

Melissa Graham, *La Trobe University*

Ann Taket, *Deakin University*

Female childlessness continues to gather momentum. Of all the women without children, it is the women unintentionally childless due to life circumstances who remain underresearched. Particularly, childless women with distance from their child-rearing years whose considered reflections can help provide further insight into this phenomenon. This hermeneutic phenomenological study aims to explore the lived experiences of women aged 60–75 living in and around Sydney who identify as circumstantially childless. Four key themes—“conservative social norms in a time of change,” “reproductive decisions and experiences,” “life as childless woman,” and “identity”—emerged from the unstructured interviews (individual and group) with 15 women revealing how they came to be childless and the impact not having children has had on their lives. It is the last theme—identity—and its four subthemes—“becoming a childless woman,” “being free,” “maternal instincts,” and “I am me”—that will be the presentation focus. This theme centres on how participants reconceptualised their sense of self beyond the label of mother and demonstrated their determination to validate their lives in pronatalist Australia where childless women are often labelled deficient or less than (mothers). This marked the first time these women spoke about their childlessness; stories laden with complexities frequently shared by the circumstantially childless. Ultimately, though the women had principally come to terms with their childlessness, it was not going to define who they were, and essentially “just got on with it.”

## **The Importance of Failing Forward When Conducting Qualitative Health Research to Address a Complex Problem**

Jennica Nichols, *University of British Columbia*

Health researchers seek to address a range of complex problems such as rising distrust in vaccines and inequities within our health-care system. Complex problems are especially hard to tackle as they are not predictable; they randomly adapt, new things emerge, and progress is not linear. Researchers are therefore challenged to nimbly evolve their work in response to the dynamic nature of these wicked problems. To do this, we need mechanisms that enable us to learn from both research successes and failures. Unfortunately, many academic and health workplaces have fail-phobic organizational cultures. In this presentation, I want to highlight the power of failing forward. Failing forward involves creating a space where we can bravely acknowledge and discuss our failures with others. By reframing failures as part of the learning process, we can discover new insights in our work while also building the capacity of other team members. First, I will share a personal failing while conducting a qualitative descriptive study about increasing inclusion and diversity within health and human services. I will then model one way you can structure a failing forward session to encourage others to host their own. Second, I will discuss lessons learned from hosting a failing forward session at a 2019 graduate conference I co-chaired at the University of British Columbia. I hope this session will illustrate the benefits of embracing failing as a natural part of qualitative research to solve complex health issues.

## **Risk of Vicarious Trauma for Graduate Student Researchers: A Scoping Review of Canadian Dissertations and Theses**

Elizabeth Orr, *McMaster University*

Pamela Durepos, *McMaster University*

Vikki Jones, *York University*

Qualitative research, in the methods employed (i.e., in-depth interviewing) and topics explored (i.e., sensitive topics such as death/dying and trauma/abuse), is emotionally demanding for all parties involved. While it is common for ethics protocols to protect research participants from emotional distress, the personal impact of emotional work on the researcher can often go unaddressed. Qualitative researchers, in particular graduate student researchers studying sensitive topics, are at risk of profound psychological effects as a result of engagement with an individual's trauma material. It is unclear, however, how this researcher impact is discussed in graduate student work and/or the steps taken to address this risk. Therefore, to provide an overview of how researcher impact is considered in Canadian graduate student research, a comprehensive scoping review of dissertations and theses was conducted. A search of student research work within sensitive topics and employing methods that posed a risk for emotional impact returned over 50,000 titles, with 562

retained for data extraction. Dissertations from 20 Canadian Universities are included in the analysis with a broad range of disciplines represented. Findings show that 81.5% of dissertations do not discuss methods to address the emotional impact of sensitive research on the student-researcher; 15.2% of dissertations describe some strategy (predominantly journaling) documenting the impact of the research and only 3.3% of dissertations had a defined protocol or plan to address the risk of emotional distress on the student-researcher. These findings suggest a need for further guidance on minimizing the risk of emotional distress among graduate student-researchers.

## **Working With Young Dynamos: The Benefits of Patient Public Involvement in Research Design**

Hilary Piercy, *Sheffield Hallam University*

Charlotte Nutting, *Sheffield Hallam University*

For any health and social care research conducted in the UK, there is a clear expectation of patient and public involvement (PPI). Funders of health and social care research increasingly stipulate that they will only give research grants where it is clear there has been PPI. Securing ethics approval for research conducted in the NHS similarly requires researchers to explain how PPI contributes to the design and/or delivery of their project. One aspect of PPI is about making sure that research is "done right." Advice and guidance from those who can provide a user perspective that broadly reflects that of the study population is invaluable in helping to ensure the appropriateness of study design and successful completion of the project. This input may be provided by working with established PPI groups, convening groups on an ad hoc basis or conducting individual consultations. For research involving young people, meaningful PPI, is essential for success but may be difficult to achieve. They are a transitional population and accessing them can be problematic. In this presentation, we share our experiences of working with Young Dynamos, a PPI group of young people who helped us to design our study which aimed to explore the experiences of growing up with a rare metabolic condition. The presentation will provide a brief introduction to the group and how they operate and then go on to explore how their involvement shaped key aspects of our study design including recruitment processes, the content and design of study materials and operational aspects of data collection.

## **Learning and Applying Mental Health Literacy and Suicide Intervention Education: A Grounded Theory Study With Youth Work Students**

Patti Ranahan, *Applied Human Sciences, Concordia University*

Child and youth care practitioners play an important role in the well-being of youth and thus, mental health literacy and

more specifically suicide prevention education, should be an integral part of child and youth care higher education programs. This grounded theory study examined how a mental health literacy curriculum, specifically designed for child and youth care practitioners, was experienced and subsequently applied in interventions with young people. As mental health literacy interventions require consideration of context and population, the curriculum intertwined dominant mental health content with youth work perspectives and principles. Practical issues such as interprofessional collaboration, professional and knowledge hierarchies, or the presence of standardized suicide intervention procedures were critically examined. Over the course of 18 months, over 60 sources of data from 13 students involved in graduate and undergraduate higher education programs and engaged in youth work internships were analyzed. This presentation focuses on the inclusion of a suicide intervention learning activity as a condition that influenced participants' learning processes. As a topic with limited traction in higher education professional programs, often included based on faculty interest or by guest lecture, teaching, and learning about suicide and suicide intervention from a critical perspective can be challenging. Participants identified suicide intervention as significantly influential on their learning process; they struggled with the dialectical positioning of presence and procedure. This struggle was amplified for some participants once engaged in practice contexts where suicide is frequently negotiated in terms of risk and responsibility.

### **Young Adolescents Experiences With Being “Stressed Out” Online: Analysis of a Digital Ambulatory Assessment Study**

Johanna Sam, *University of British Columbia*

Jennifer Shapka, *University of British Columbia*

Understanding young people's social media use has become a priority among healthcare providers and researchers due to impact on adolescents' mental health with immediate and long-term consequences. Particularly, time spent on social media has been associated with anxiety and depression. Despite growing concerns about time spent online, few researchers have explored its complexity in every-day-life situations among youth. The present study addresses this gap by utilizing digital ambulatory assessment to explore momentary real-world online interactions among young adolescents. The initial analysis of 372 text entries and 44 digital media data provided by  $n = 53$  youth participants in British Columbia between ages 11 and 15 in CyberKids Live Study emerged a health-related theme of “stressed out.” Participants described the negative impact online experiences had on them; for example, one youth reported, “she makes me so mad and when she Snapchat's me I get

this gutty feeling in my chest and it turns my day from good to bad...but I can never get away from her because of social media: (sometimes, I wish I could just block her or remove her from my Snapchat, but then I would really be in for it and she's just begging for drama.” Study findings highlight the importance of peer relationships for health providers and educators to prevent stressful online experiences among youth. Exploring negative online experiences has meaningful implications for understanding the connection between how teens appraise stress arising online and their well-being.

### **Gaps and Absences in Nursing Workload Measurements: Failing to Theorize Nursing as a Practice**

Meiriele Tavares-Araujo, *School of Nursing at Federal University of Minas Gerais*

Christine Ceci, *Faculty of Nursing, University of Alberta*

Mary Ellen Purkis, *School of Nursing, University of Victoria*

Nursing workload measurements produce a particular view of nursing work. This view has an influence on organizing the work of nurses. These measurements are usually structured with the goal of attaining a “perfect match” between patient care needs and nursing care provided. This model of a perfect match has effects on nursing practice mainly when patients' care needs and nursing work are conceptualized as discrete tasks, and nurses' work is assumed to be undertaken only in a direct relationship with patients and at the bedside. In contrast, we argue that nursing, rather than a discrete set of tasks, is better understood as complex practice, which discrete tasks hold their importance because of the pattern of connections that embrace the practice together. Nursing should acknowledge as practice considering that it happens in a connection-in-action and an interweaving of nurses, patients, institutional routines, temporality, and materiality. Nursing practice, along with direct patient care, comprises management, teaching, and policy and knowledge development. In this article, we examine the knowledge of nursing produced through nursing workload measurements that we argue misrepresents the nature of nursing work in significant ways. The search conducted across five databases provide data for a systematic scoping review about nursing workload measurement in hospital settings. Primary findings suggest that nursing work has been understanding through the gaze of the nursing workload measurements. These measurements are (re)shaping nursing practice as a group of nursing tasks and nonnursing tasks and can be delegated to other professionals of health or nonhealth field.

## **“When You Are Black, Male, Gay, and on Top of That, You Have HIV . . . oooh, It’s the Icing on the Cake”: Reframing Marginalized HIV+ Men in the United States With Photovoice and Documentary Film**

Michelle Teti, *University of Missouri*

Katina Bitsicas, *University of Missouri*

Michael Reece, *KC Care Clinic*

Black men who have sex with men in the United States suffer disproportionately from HIV and face intersecting stigmas (e.g. ethnicity/HIV status/sexual orientation) that compromise their health. We conducted a Photovoice project with this population ( $N = 15$ ) to learn more about men’s HIV intervention needs (e.g., to promote healthy behaviors like medication adherence) amid these stigmas. The Photovoice process included two group photo-sharing discussions about stigma and health, and follow-up emails and one-on-one conversations to clarify photos’ meaning as needed. For the “action” component of the project, the participants decided collectively to create a documentary, from the stories that arose during Photovoice, to showcase their challenges and their resilience to staying healthy. The goal of the documentary was to decrease stigma among other men with HIV and HIV-negative audiences. To create the documentary, we analyzed Photovoice data via theme analysis to identify key concepts in stories/images. Resultant themes to be explored in the documentary included becoming HIV positive, health challenges and motivations, stigmas, the “Black church,” family (particularly fathers) and community, learning from HIV, and saving other men at risk. Then, we conducted additional one-on-one video interviews about these seven themes and worked with film students to create the documentary (excerpts to be shown in presentation) with interview footage. The documentary will be presented to men living with HIV and an HIV-negative audience of health professions students in Fall 2019. Evaluation of the documentary will capture changes in attitudes and stigma towards Black, gay, men living with HIV.

## **Pictures of PCOS: Experiences of Polycystic Ovarian Syndrome Through Drawings**

Cassandra Thorpe, *University of Alberta*

Kelly Arbeau, PhD, *Trinity Western University*

Benjamin Budlong, *Trinity Western University*

Polycystic ovarian syndrome (PCOS), a chronic endocrine disorder affecting up to 10% of postpubertal individuals with ovaries, is associated with persistent physical symptoms and a range of psychological and lifestyle effects. In recent years, the literature has begun to explore what it means to live with the wide range of symptoms and medicalized experiences associated with PCOS. The present study investigated perceptions of those diagnosed with PCOS through drawings and personal reflections. Adult

participants ( $n = 89$ ; 83 female, 6 nonbinary) were asked to draw their PCOS as it most commonly affects them, reflect on the image, and then describe the image they created. Responses were analyzed using Rose’s critical visual methodology by three independent raters; ratings were compared for agreement and discrepancies discussed in a team meeting. Four descriptive themes were identified: awareness of visible and invisible symptoms, misshapen self and body, limitations and barriers, and resignation. Participants described PCOS as a “villain” that seizes positive self-worth, emotions, life goals, and femininity. Results both replicate and extend previous findings using different methodologies, providing evidence of convergent validity across methods but also a broader understanding of participant concerns about living with PCOS. Strengths of the study include the use of a visual methodology and an inclusive recruitment strategy (online study, recruited participants of all genders with PCOS).

## **What About the Researcher’s Mental Health?**

Gabriela Trombetta Santos, *Federal University of São Carlos*

When elaborating a qualitative research project, professors and students are always concerned about ethical questions related to participants’ safety, finding different ways to protect them from any kind of damage or suffering. A question we do not usually ask is: What about the ethical decisions we can take regarding the mental health of the one conducting the research? In this sense, the aim of this presentation is to shine a light on my personal experience of conducting individual interviews with Brazilian adolescents who show symptoms of depression and anxiety disorders, discussing important ethical decisions we may reconsider when thinking about study design regarding interviews, for example, taking into account more seriously the number of participants we aim to have in contrast with the number we could really have considering a healthy schedule, settling a limited number of sessions per day, enough time between sessions, extra time for biological and leisure activities and might considering have an personal counselling available during the phases of data collection and transcription.

## **Embodied Dialogue and Possibilities for Change: Using Forum Theatre to Explore Indigenous Content in Nursing Education**

Vanessa Van Bower, *University of Manitoba*

Roberta. L. Woodgate, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Donna Martin, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Frank. Deer, *Faculty of Education, University of Manitoba*

Integrating Indigenous knowledge, teaching methods, and understanding Indigenous lived experiences remain at the heart

of the Canadian educational agenda and have been enacted as priorities in Manitoba through the Manitoba Collaborative Indigenous Education Blueprint (MCIEB). This study explored the use of a forum theatre (FT) as a culturally relevant pedagogy for nursing educators, health care providers (HCP), and students to engage in the priorities of the MCIEB. The central objectives were to (1) facilitate a dialogue through FT regarding several of the priorities of the MCIEB with nursing educators, HCPs and students; (2) explore possibilities for integrating the priorities of the MCIEB within nursing education; and (3) explore nursing educators', HCPs', and students' experiences of FT as a pedagogical approach. Using an arts-based participatory methodology, nursing educators and HCPs ( $n = 9$ ) collaboratively created a FT play that they performed to an audience of students. Nursing educators and HCPs from Manitoba were recruited via snowball sampling and agreed as inclusion criteria to be videotaped during the workshop and the play. Current undergraduate and graduate students at the University of Manitoba ( $n = 7$ ) were recruited via purposive sampling and agreed to be videotaped and photographed during the FT play. Data collection included the playbuilding workshop, the script, the performance of the FT play, audience interventions, and a postplay discussion. Data were analyzed using content and form analysis. Rigour was ensured through coreflexive member and advisor checks. This study contributes to advancing reconciliation within nursing education and to the knowledge about FT as a nursing pedagogy.

### **Rumination and Risk: Exploring Sexual Health Anxiety Among Online Sexual Health Chat Service Clients**

*Sarah Watt, BC Centre for Disease Control*

Acute and chronic (repeated) expressions of anxiety are common among sexual health service clients, yet little is known about how sexual health providers can best support highly anxious clients. The anonymity and accessibility of online sexual health services may offer unique opportunities to connect clients with appropriate mental health supports. Using data from the BC Centre for Disease Control's SmartSexResource anonymous online chat service, we sought to characterize (i) the presentations of anxiety among chat users and (ii) nurse responses to anxiety among chat users. We analyzed 48 transcripts between January 1, 2017, and December 31, 2018, using an inductive thematic analysis. During preliminary analysis, we identified (i) pronounced worry, anxiety, and emotional distress, particularly regarding HIV (e.g. acquisition, perceived symptoms, testing accuracy) in the absence of any nurse-assessed HIV risk; (ii) exaggerated appraisal of HIV-transmission risk among chat users who described shame and stigma related to their sexual behaviours; and (iii) patterns of rumination in which clients return to chat with similar presentations that were unresolved by HIV education or testing interventions alone. Although nurses often recognized and acknowledged worry and anxiety among chat users, their responses to this worry varied widely and were constrained by a scarcity of known and reliable referral

options. More evidence is needed in order to identify appropriate, effective, and acceptable interventions for anxiety among sexual health service users. Future chat support tools and focused training may support online sexual health providers in responding to specific and identifiable forms of sexual health anxiety.

### **Paramedics Working in a Prison Based Healthcare Setting: A Qualitative Exploration of the Impact on Interprofessional Working**

*Julia Williams, University of Hertfordshire*

*Lewis Johnson, University of Hertfordshire*

Prison healthcare departments in the United Kingdom have recently started recruiting paramedics to assist in dealing with a rise in medical emergencies attributed to increasing Novel Psychoactive Substance misuse, which is a real challenge in prison settings currently. There has been little research investigating the paramedic role in this new setting. This study explores the strengths and limitations of interprofessional healthcare working within the prison healthcare setting from the perspectives of nonparamedic staff. An exploratory, generic qualitative research study was conducted in a UK category B remand prison, focusing on the observations of current healthcare and custodial staff using a multi methods approach to gather qualitative data. Seven global themes were identified through processes of thematic analysis: management of medical responses, effect of a specialist role, effect on ambulance escorts, contribution to professionalism, effect on the role of other healthcare staff, prisoner interaction with paramedics, and difficulties encountered in role implementation. The findings highlight the complexity of implementing a new role into an established healthcare system, and this presentation will discuss the strengths and limitations observed by those in regular contact with the paramedics. The extension of clinical experience and training provided by paramedics appears to provide a sense of support and reassurance for other healthcare staff who would previously have been required to step outside of their levels of competence and training to meet increasing demand. This study postulates that paramedics possess the relevant skills and training to offer a meaningful contribution to the provision of prison healthcare.

### **Oral Presentations**

#### **Drinking Cultures of Rainbow New Zealanders**

*Jeffery Adams, Massey University*

*Stephen Neville, Auckland University of Technology*

Rainbow New Zealanders (i.e., people with diverse sexual orientations other than heterosexual, diverse gender identities

and experience, or diversity of sex characteristics) drink alcohol at heavy and problematic levels. This study investigated factors that contribute to drinking among these groups and identified potential areas of health promotion intervention. The study used face-to-face focus groups as this method is excellent for obtaining cultural discourses and shared cultural information. Twenty-four “affinity” focus groups were undertaken across six cities involving 131 participants. The participants were recruited by a diverse group of Rainbow people from among their friends and acquaintances. A social constructionist informed thematic analysis was used in order to identify the sociocultural contexts of drinking. The study found three interacting influences (drinking norms and environments, e.g., heavy New Zealand binge drinking culture; specific Rainbow influences on drinking, e.g., coping with exclusion and stigma; and promotion of alcohol and drinking, e.g., gay-specific alcohol advertising) and limited provision of effective health promotion and alcohol health services were viewed as affecting drinking behaviors and practices. Using these results, a number of areas of health promotion interventions were developed. These focused on addressing sociocultural contexts and structural conditions that promote drinking by Rainbow individuals and groups. They included embracing diversity; reshaping drinking norms; reducing discrimination, stigma, and exclusion; improving alcohol health promotion and services; and reducing reliance on alcohol industry sponsorship. Continuing to focus health promotion at the individual level is unlikely to bring about significant change to problematic drinking behaviors.

### **Asian Gay and Bisexual Men in New Zealand Have Poor Knowledge of HIV Preexposure Prophylaxis (PrEP)**

Jeffery Adams, *Massey University*

Jed Montayre, *Auckland University of Technology*

Stephen Neville, *Auckland University of Technology*

Preexposure prophylaxis (PrEP) is a novel biomedical HIV intervention recently publicly funded in New Zealand. However knowledge about PrEP and use of it has been found to vary among different groups. In order to investigate Asian gay and bisexual men’s (GBM) knowledge and views about PrEP an interview study was undertaken. Nineteen interviews were completed in Auckland—New Zealand’s largest city which has disproportionately large proportions of GBM and Asian people. Participants comprised men who had immigrated within the past 7 years and were not using PrEP. The thematic analysis was informed by critical realism, which theorizes people’s accounts as constructed, yet at the same time accepts them as descriptions of events and personal experiences that have some basis/meaning in reality. Three themes were identified in relation to the men’s talk about PrEP. Firstly, “I’m not sure what PrEP is” in relation to the reporting of limited and at times incorrect understandings of PrEP was the dominant framing

in the men’s accounts. Secondly, “PrEP is not proven” in relation to men expressing concern about whether the effectiveness and safety of PrEP medication had been proven. Thirdly, “PrEP is for highly sexualized people” in relation to a viewed expressed that PrEP is for other men who are more sexually active than them. Taken together, the results suggest focused health promotion interventions are required to raise the awareness of the benefits of PrEP among Asian men. Doing this will contribute to reducing the disparities in sexual health experienced by these men.

### **A Qualitative Synthesis of Theories on Psychosocial Response to Loss of Breasts, Limbs, or Teeth**

Maha M. Al-Sahan, *Faculty of Dentistry, University of British Columbia*

Michael I. MacEntee, *Faculty of Dentistry, University of British Columbia*

Sally Thorne, *School of Nursing, University of British Columbia*

S. Ross Bryant, *Faculty of Dentistry, University of British Columbia*

The aim of this systematic review is to generate a qualitative synthesis of psychosocial theories that seeks to explain the beliefs and behaviors of people responding to loss of anatomical parts, such as breasts, limbs, or teeth. A search of four databases and the grey literature identified potentially relevant articles. Three investigators read each included article and, by consensus, analyzed the findings through a three-stage interpretive process to deconstruct and interpret each theory, categorize similar theoretical constructs, and distill the dominant theoretical perspectives identified as most relevant to explaining responses to the loss. The search yielded 2,540 citations, from which 288 articles referred to 89 relevant primary theories containing 586 constructs. We synthesized seven construct categories integrated from five dominant theories relating to communications, developmental regulation, emotions, resources, and social cognition. This qualitative synthesis provides a conceptual foundation for further investigations to explain how people manage loss of anatomical parts.

### **Building Capacity for the COPD Community Through Digital Technologies: A Transformative Mixed Methods Research Study**

Marcy Antonio, *University of Victoria*

Digital technologies (DTs; e.g., social media and Skype) are providing new avenues to support social connectedness and health outcomes. The progressive shortness of breath,

fatigue, and frailty experienced with chronic obstructive pulmonary disease (COPD) can lead to compounding social isolation. Additionally, a demonstrable link has been found between lower socioeconomic status and increased prevalence and negative outcomes of COPD. To understand how to address the social and health inequities experienced by people with COPD, a transformative mixed methods research (MMR) study is being conducted. Over three stages (qual-quant-qual) people are being asked to share their knowledge on how DTs can support social connectedness and COPD. In this presentation, I will discuss how the recruitment process and qualitative findings from the first-stage further highlight the urgency in building capacity for this socially isolated and excluded community. To reach a diverse COPD population, recruitment was done broadly across numerous community and healthcare organizations. Semistructured interviews ( $n = 7$ ) were conducted in-person or through the person's preferred communication technology. Narrative analysis was supported through coding in AtlasTi and writing within narratives. People's use of DTs was dependent on their previous work experience and what friends' and families' were using. Some individuals referenced alienation, while others spoke about connecting with people all over the world. These and other first-stage findings will contribute to the overall analysis of the MMR study and to inform the selection of measures and survey development that will be used to further evaluate the role DTs play in supporting social connectedness for COPD.

### **Do Patients and Healthcare Providers Agree on the Barriers and Facilitators of a Patient Portal Implementation and Adoption—A Qualitative Comparative Case Study**

Melita Avdagovska, *School of Public Health, University of Alberta*

Karin Olson, *Faculty of Nursing, University of Alberta*

Tania Stafinski, *School of Public Health, University of Alberta*

Devidas Menon, *School of Public Health, University of Alberta*

Digital storage and communication such as the electronic health record have had a significant impact on healthcare in recent years. With the increased shift to patient-centred care, patient portals, which provide access to important personal health information and allow communication with providers, have become more prevalent. In Alberta, where there is a major province-wide implementation of an EMR underway, Alberta Health Services is piloting a patient portal, MyChart, to (1) determine whether it helps facilitate partnerships between patients and providers and improves health outcomes and to (2) identify ways of improving its

effectiveness prior to province-wide deployment. Although MyChart allows patients to view appointments and selected lab results and communicate with their health providers, its impact has not been as projected and uptake has varied. A qualitative comparative case study approach was used. Semistructured interviews were conducted with such individuals from five clinics. Patients were asked about the impact of MyChart on their health and health care. Providers were questioned about the impact on the patient/provider relationship and workflow. Managers were asked about barriers to implementation. Interviews were entered into NVivo and coded for main themes derived from the questions asked of each group. These themes are currently being developed into key concepts. In this presentation, we will present an initial model of links between these concepts that explain the variation in uptake of MyChart during the current pilot.

### **Tracing the Decisions that Shaped the Development of MyChart, an Electronic Patient Portal in Alberta Canada—A Historical Research Study**

Melita Avdagovska, *School of Public Health, University of Alberta*

Karin Olson, *Faculty of Nursing, University of Alberta*

Pauline Paul, *Faculty of Nursing, University of Alberta*

One of the key challenges related to health information technology (IT) investments is demonstration of their impact on quality of care. There is a high rate of failure and a tendency to downplay the complexity of the development and implementation process. Decision makers need to understand what to consider prior to funding and implementation. The focus of this historical study was to examine the institutional decision-making processes that shaped the development and implementation of MyChart, an electronic patient portal used in a Canadian province. The study was based on a seven-step framework that included a rigorous archival analysis (internal and external criticism) of documents and interviews with 10 key decision makers. The goal of data analysis was to understand the decision related to the development and implementation of MyChart and factors that influenced these decisions. The results document the effect of various social and political spheres of influence on the development and implementation of MyChart and identify the key factors that government and healthcare organizations may wish to consider prior to funding IT in healthcare. In this presentation, we will discuss several findings that should be considered by decision makers. These include implementation disruptions, essential skills for the leaders, learning needs' assessment of users, how to avoid duplication, the need for buy-in, and evaluation considerations.

## **Cancer Rehabilitation: A Constructivist Grounded Theory of Patient Empowerment**

Jonathan Avery, *Princess Margaret Cancer Centre*

Doris Howell, *Princess Margaret Cancer Centre*

Claire-Jehanne Dubouloz-Wilner, *University of Ottawa*

Roanne Thomas, *University of Ottawa*

“Patient-empowerment” is a phenomenon ubiquitous with cancer rehabilitation. Defined as a process and an outcome of taking control, empowerment has become a desirable experience through which people are able to address functional concerns as well as quality of life issues that are impacted by their cancer. Yet, empowerment remains a phenomenon not fully understood. The purpose of this submission is to present a grounded theory of patient empowerment specific to cancer rehabilitation. Semi-structured interviews with 22 cancer survivors (cancer of the head or neck and or breast) was the primary means of data collection. Interviews explored participants’ illness experiences and views of empowerment. The social constructivist grounded theory method was applied to analyze and map the processes of empowerment. Findings illustrate that empowerment occurred in two dynamic and paradoxical ways: (1) establishing control over the impact of the illness on participants’ daily lives as a means to circumvent a sense of self that was eroding and changing and (2) relinquishing control over aspects of the illness deemed irrepressible and incorporating those aspects into a new identity. The first set of processes of this theory is comparable to current evidence-based practice in cancer rehabilitation that has a dominant focus on control over body functions and structures to reduce the impact of the illness on daily life. Gaps are more significant in relation to the empowerment processes associated with relinquishing control. Thus, this grounded theory provides a framework to build upon and develop novel ways to approach the rehabilitation of cancer survivors.

## **Experiences of Fathers With Inflammatory Arthritis: A Grounded Theory**

Catherine Backman, *University of British Columbia*

Michal Avrech Bar, *Tel Aviv University*

Thao Dao, *WorkSafeBC*

Leah DeBlock Vlodarchyk, *Fort Saskatchewan Community Hospital*

The impact of inflammatory arthritis (IA) on men’s perspectives on parenting has not been fully explored. We sought to describe fatherhood experiences, the effect of IA on parenting activities, and strategies used by fathers with IA to fulfill their role. Given minimal prior research on fatherhood and IA, a grounded theory approach was chosen to guide in-depth interviews. Nine men with IA and at least one child under 19 years at home were

recruited through rheumatology practices, therapy clinics, and social media. All were married, ages 31–62, with one to five children. Seven were employed (three on disability leave, one on parental leave) and two had disability pensions. Analysis involved a series of iterative steps to develop key themes and a preliminary explanatory framework of fathering experiences of men with IA. “Being an involved father” describes participants’ perspectives on being hands-on parents, role models, and financial providers. “Taking ownership” explains how participants managed daily life, comprised of two subthemes, “taking care of yourself” using strategies like exercise and communicating with loved ones, and “redefining yourself,” a process of adapting to reframed identity and lifestyle adjustments. “Accessing and receiving support” indicate men felt well-supported by social networks (most critically their wives), health care providers, and information sources. The grounded theory offers an enriched understanding of fatherhood experiences of men with IA. When social, practical, and educational supports are in place, men with IA find parenting joyful and rewarding and are largely unrestricted by arthritis in fulfilling their role as fathers.

## **Older Adults’ Experiences of Using Cannabis in Later Life**

Jennifer Baumbusch, *University of British Columbia*

Isabel Sloan Yip, *School of Nursing, University of British Columbia*

Cannabis prohibition ended in Canada in October 2018. While cannabis use in most age groups is on the rise, research exploring cannabis use among older adults is quite limited. Past research has indicated that older adults tend to use cannabis for medicinal purposes, including pain management, appetite stimulation, and sleep assistance. The purpose of this study was to explore older adults’ experiences of starting to use cannabis at age 65 years or later. The study was informed by critical gerontology and employed qualitative description. We recruited 11 older adults from across Canada who had started using cannabis at age 65 later. Two men and nine women, ranging in age from 71 to 85 years (average age: 76) participated in semistructured interviews. We found that most participants were using recreational cannabis for medicinal purposes without consulting or informing their primary health-care providers. As well, most of the participants obtained information about cannabis from store staff and purchased cannabis from stores that are not appropriately licensed to sell for medicinal purposes. Some of the participants were hesitant to share their cannabis use with their social networks because of shame and the perception that older adults do not use cannabis. In this population, the factors identified around information sources and purchasing patterns may have unforeseen consequences for health. There is a clear need for better public education for older adults about the cannabis industry as well as education for healthcare professionals working with this population in order to provide evidence-informed education and support.



## **Recruitment Tensions: Lessons Learned on Accessing Proxy Decision Makers of People With Dementia**

Haley Bent, *Alberta Health Services*

Kimberly Shapkin, *Alberta Health Services*

Colleen Cuthbert, *University of Calgary*

Recruiting for qualitative studies can be one of the most resource intensive aspects of the study process. Many factors can determine the effectiveness of recruitment, including researcher, institutional and participant characteristics. We conducted a qualitative inquiry using focus groups to explore proxy decision makers understanding of frailty and their perspectives on the utility of a frailty measure. In trying to recruit proxy decision makers for persons living with dementia, a number of challenges and successes were identified by the research team. The team had many established relationships with institutions, organizations, and governmental ministries which interact directly with persons living with dementia and their proxy decision makers. As well the researchers were very familiar with the topic of dementia and communicating this with clients and their families. However, institutional barriers were encountered in trying to access proxy decision makers for persons living both at home and in facility and in trying to access government employed public guardians for persons living with dementia. There was also a lack of diversity amongst the proxy decision makers which created challenges in the makeup of the sample. A review of the barriers was completed and determined that not all could be overcome. Identification of the recruitment challenges and barriers was essential to understanding our study results and is considered to be as important as the study findings themselves. Several lessons were learned by the novice research team to take forward and apply in the future.

## **Relatives and Health Care Personnel Needs When Facing the Death of a Patient in ICU: Different Voices and Conflicting Perspectives**

Margarita Bernales, *Pontificia Universidad Católica de Chile*

Paula Repetto, *Pontificia Universidad Católica de Chile*

Despite improvements in health care, around 50% of patients will die at the ICU. This high prevalence has raised concerns about how health care personnel cope and respond to the needs of relatives of the patient. The aim of this study was to explore the needs of relatives and those from the health care providers from an ICU when a patient dies. Conducted a qualitative and collective case study. We conducted 10 semistructured interviews with ICU personnel (three physicians and seven nursing professionals), and 10 relatives of patients who had died within 6 months of the study. All interviews were performed by trained graduate students in psychology and transcribed ad-verbatim. A thematic analysis was

done using NVivo Version 11. Procedures were approved by Local Ethics Committee and participants signed informed consent. Main relatives needs include (1) receive clear and prompt information about the condition of their loved ones, (2) provide prompt information about changes in patient's condition and new interventions, (3) flexible visit times and allowed visitors, and (4) provide emotional support to relatives. ICU discussed (1) lack tools to provide emotional support to families when delivering bad news, (2) problems handling their own mourning when patients die, and (3) inconsistent responses among personnel on how to respond to relatives' needs. Implementing rituals, access to consultation and support, are recommended. Relatives have a more shared perspective as compared to providers. From these findings, we are planning a protocol to implement when patient will soon die to address relatives' needs.

## **Third Eye Seeing: Exploring Decolonial, Intersectional Pedagogies in Canadian Nursing and Medicine**

Taqdir Bhandal, *University of British Columbia*

Annette J. Browne, *University of British Columbia*

Cash Ahenakew, *University of British Columbia*

Sheryl Reimer-Kirkham, *Trinity Western University*

The Third Eye Seeing project investigates if and how decolonial, intersectional perspectives (DIP) inform Canadian Nursing and Medical (NursMed) education. The purpose is to contribute to the ongoing development of NursMed education and national efforts to redress health inequities. Decolonial theories of research foreground the relationship between humans, the earth, and ownership. In Canada, this means repatriating land and life back to Indigenous communities. Intersectionality refers to an analytic lens that examines "intersectional" identities corresponding with people's experience of power and social structures like colonialism. As such, DIP are philosophies of learning that encourage teachers and students to engage their practice through the lenses of settler-colonialism, social justice, and health equity. In this presentation, we provide an analysis of research conducted as part of Third Eye Seeing with NursMed professors from various universities in Canada. Using critical ethnographic methods we are documenting stories, strategies, and struggles through in-depth interviews with 15 key leaders in the field of DIP. Analysis of these data are supplemented by classroom observations and textual analysis of select course syllabi documents. The preliminary findings of the Third Eye Seeing project show that making space for DIP might require decentering the ego of (primarily settler) teachers and students. More importantly, constructing racialized self-awareness, epistemological pluralism, and a strong social justice oriented collective goal within NursMed education. In the presentation, we reflect on implications for qualitative health research. This includes our

process of fieldwork to date, and opportunities for DIP in modern health research, including NursMed education.

### **Examining Emancipatory Potential: Interpretive Phenomenological Analysis and Social Work Health Research**

Aline Bogossian, *Department of Social Work, Université de Montréal*

Denise Brend, *Department of Psychoeducation, Université de Sherbrooke*

Interpretive phenomenological analysis (IPA) is a qualitative research method originating in the field of psychology to document experiences of physical and mental health. IPA provides tools to engage with research participants in the pursuit of “a detailed examination of a lived experience”. The importance given to experiences of individual IPA research participants coincides with the value of respect for the inherent dignity and worth of persons in social work professional code of ethics (CASW). Researchers thus join with participants to explore experiences that may be concealed by biased assumptions, practices, or hegemonic portrayals. However, little guidance is provided about how to use this method as an emancipatory tool or how to avoid reproducing oppressive research practices in the pursuit of social justice (another social work value). The objective of this article is to examine convergence and divergence between IPA and social work values. Drawing upon the case examples of two IPA-inspired studies undertaken in the field of social work: Investigating the meaning of “involvement” among fathers of children with neurodisabilities, and workplace social support among intimate partner violence social workers, the convergence of IPA with social work values is explored, then divergence or gaps encountered are discussed. An initial framework for establishing coherence of IPA with social work values and skills is proposed including recommendations for how IPA can be enriched to serve as an emancipatory tool. Implications for future research and the potential of IPA to promote social emancipation is discussed.

### **Qualitative Weave: Integrating Qualitative Methods in a Leading Public Policy Program**

Nathan Boucher, *Sanford School of Public Policy, Duke University*

Operating in a public policy graduate program strong on quantitative methods, often excluding qualitative approaches, and replete with generalist public policy and corporate consultant aspirants, I was tasked with simultaneously (a) expanding the qualitative methodology offerings and (b) increasing the health care policy offerings—both requested by several cohorts of graduate public policy students. What resulted was a well-received—and evolving—qualitative-oriented tapestry which includes (1) an undergraduate course in U.S. health systems

delivery with emphasis on research showcasing the patient and caregiver voice as well as perspectives from multiple health professions, in-person; (2) a graduate course in general qualitative research methods adapting my experience in qualitative health services research with its ethos of lifting voices to inform policies and improve health care quality in all areas; (3) a specific course in qualitative methods in health services research subscribed to by graduate students from diverse concentrations; (4) a 2-day seminar on qualitative methods and mixed methods incorporated into the first year introductory master’s course in applied public policy; and (5) proactive advisement for master’s and doctoral students pursuing qualitative and mixed methods in their projects, not previously done. I will focus on one to two key challenges and one to two keys to success of delivering each of the five components above which were intended, in concert with school leadership, to enhance the quality of comprehensive research methods training for both undergraduate and graduate students training at a top-tier research university in the American South.

### **“She’s Exactly How She Should Be”: Parents of Children With Newly Diagnosed Disorders of Sex Development Identify Major Concerns**

Nathan Boucher, *Sanford School of Public Policy, Duke University*

Hassan Alkazemi, *School of Medicine, Washington University*

Jonathan Routh, *School of Medicine, Duke University*

Disorders of sex development (DSD) are congenital conditions acquired before birth where development of chromosomal, anatomical, and/or gonadal sex is atypical. These conditions affect 13/100,000 newborns every year. While DSD terminology is controversial, the experience of the conditions can be deeply personal and complex for individuals and their parents alike. Treatments can impact anatomical function, gender identity, and experiences of discrimination. Little is known about how parents manage their feelings and actions upon learning of such a diagnosis with their newborn. This qualitative study involved in-depth, semistructured interviews with six parents of children with DSD treated at our multidisciplinary center. Due to the sensitive and highly personal nature of DSD diagnosis and treatment, this is a historically difficult-to-recruit population. Descriptive content analysis with inductive approach helped determine themes. Themes were organized by (a) societal impact (bullying, need for secrecy, and future desirability), (b) family impact (relationships with parents/siblings, parental guilt), and (c) personal impact (gender/sexual identity, anatomic function, and mental health). Implications for clinicians include modifying medical education and bedside approaches to be more sensitive to these issues. Implications for parents include increasing empowerment, advocacy, and support for them following diagnosis. Implications for health and social service organizations include development of

enhanced education for providers, modified approaches to patient care on clinical teaching services, and bolstering communication and support for parents and children. DSD presents challenges for delivery of health and social services but also opportunities to discuss and refine the way we, as a society, view gender and sex.

### **Exploring the Dynamics of Structure and Agency in Patient and Staff Experiences of Using Electronic Repeat Dispensing**

Cindy Brooks, *University of Southampton*

Catherine Brigitte Matheson-Monnet, *University of Southampton*

Anastasios Argyropoulos, *University of Southampton*

Electronic repeat dispensing (eRD) introduced by the NHS for primary care in 2009 became part of a contractual requirement for all general practices in England this year. Whilst eRD is promoted to improve efficiency for General Practitioners and Community Pharmacists, and offer choice for patients, there is limited research on the experiences of those using eRD. To address this gap and also to understand why the use of eRD is lower (10%) in Wessex in comparison to England (14%), this study explores the perceptions and experiences of patients and staff working in General Practice and Community Pharmacy using eRD in Wessex. Data collection included a survey with 36 respondents (7 patients and 29 staff) and 10 in-depth telephone interviews (5 patients and 5 staff). Guided by Giddens structuration theory, qualitative analytical findings show how patient and staff perceptions and experiences of eRD are shaped by a complex dynamic of structure and agency, manifesting through three thematic spheres: (i) patient needs and preferences, (ii) organisational and cultural factors, and (iii) structural forces involving sociohistorical, economic and political factors. Analysis also provides exploration of the unique challenges and benefits of using eRD for patients and staff as well as recommendations for improvement. Whilst providing understanding into the interaction of individual, organisational, and structural influences shaping use of eRD, these findings also offer holistic insight into the perspectives and challenges involved in implementing a digital technology.

### **Quality of life in Hospice: Interactions Among Temporal, Occupational, and Relational Dimensions**

Laura Nimmon, *University of British Columbia*

Laura Yvonne Bulk, *University of British Columbia*

Gil Kimel, *St. Paul's Hospital Palliative Care Program*

Nigel King, *University of Huddersfield*

Individuals at the end of life (EOL) and their loved ones have unique temporal experiences. Their temporal experiences are

both influenced and mitigated by occupational engagement and disengagement and by the relationships in their lives. Although temporality, occupation, and relationships are identified as discrete factors that impact quality of life, we have little insight regarding whether their interaction shapes the quality of life for individuals in EOL care and their loved ones. Previous studies focus on one of the factors. Scholars, practitioners, and educators require insight into the interaction of these factors that shape the quality of EOL to foster enriching and meaningful EOL experiences. This study is framed by a constructivist understanding that meaning is negotiated between people through social interaction and occupational engagement in temporal contexts. We ask how do relationships, temporality, and occupation inform one another at EOL in hospice? We conducted in-depth interviews with 9 patients and 10 loved ones, including completion of Pictor charts—visual representations of patients' relational worlds. Analysis was conducted through an iterative process involving open, axial, and selective coding. We explore the findings as three main processes: (1) experiences of temporal rupture, (2) diminished significance of clock time, and (3) shifts in occupational priorities. Bringing awareness to these processes can foster more sensitive EOL care that is attuned to the complex meaning making of patients and loved ones. Participants' perspectives may help carers understand how to foster positive temporal experiences and quality of life for patients and loved ones.

### **Blurry Lines: An Examination of Two Blind or Visually Impaired Researchers' Experiences of "Insider" Research**

Laura Yvonne Bulk, *University of British Columbia*

Bethan Collins, *University of Liverpool*

Reflexivity and questioning researcher positionality are core to trustworthy qualitative research. This study problematizes the concept of "insider" research—where researchers share experiences or identities with participants, such as chronic health conditions or disabilities. This study is conceptualized within disability studies discourse, which advocates for disabled people to undertake disability research, which may be more relevant to the disabled community. Undertaking such "insider" research comes with challenges and opportunities. Little is known about how, for blind people, the experience of insider research impacts the process or the researchers. Using an auto-ethnographic approach, this study explores experiences of two blind researchers. It examines perceptions of the challenges and benefits of insider research and the strategies used to promote reflexivity. Data were collected through asynchronous online conversations between two participant-researchers. Data were thematically analyzed by each researcher and integrated to draw key findings. We found that insider research is complex: It is a perception or feeling, likely not a binary "insider" or "outsider" experience but rather a feeling of the extent to which one can be an insider in any situation. Sharing a

characteristic does not necessarily enable a sense of “insiderness.” Strategies undertaken in insider research include field notes, journaling and self-reflection, and doing insider research is characterised as “difficult” emotional and intellectual work. Although focused on the lived experience and navigation of insider research as blind scholars, the findings may inform individuals considering insider research from a variety of health-related perspectives.

### **Patient Perspectives: Four Pillars of Professionalism**

Laura Yvonne Bulk, *University of British Columbia*

Donna Drynan, *University of British Columbia*

Sue Murphy, *University of British Columbia*

Patricia Gerber, *University of British Columbia*

Professionalism is a core component of healthcare practice and education; however, there is often not a consistent description of professionalism, and current definitions lack a key perspective, that of the patient. This study aimed to deepen understandings of patients’ perspectives on how professionalism should be enacted by healthcare providers. Using a phenomenological approach informed by constructivist theory, the interprofessional team conducted semistructured interviews and focus groups with 21 patients to explore their views on professionalism. Data analysis was conducted using a constant comparative approach wherein initial analysis informed subsequent data collection. Participant themes fell into four pillars of professionalism: taking a collaborative human-first approach, communicating with heart and mind, behaving with integrity, and practicing competently. This study highlights patient perspectives on professionalism and examines consistencies and differences between those perspectives and those of healthcare providers, which are extensively described in the literature. Although published literature highlights competence and communication as main aspects of professionalism, our participants also highlighted these while focusing more emphasis on integrating patients into care teams, employing empathy, and demonstrating integrity.

### **Narrating Shared Illness Experiences: Mothers of Children With Tay-Sachs Disease**

Julia Campos Climaco, *University of British Columbia and Universidade de Brasilia*

Illness experiences create breaches in canonical narratives and demand meaning making in narrative’s reenvisionings. This presentation explores data from a narrative study, produced through oral life history interviews of seven women whom have or had children with Tay-Sachs, a rare neurodegenerative disease that causes death in early childhood, with no acknowledged cure. The children’s illness experiences and narratives are shared by their mothers because they are the ones who can

narrate their short lives and because the mothers’ experience as main caregivers made the illness experience decisive to their own life stories. The analysis was informed by the concept of moral laboratories: a metaphorical space of imaginative experimentation where people test life’s possibilities to create moral projects to live good lives, contradicting statistics and prognosis. Results indicate that the mothers made meaning for their atypical motherhood and found ways to keep their children alive even after they died. The women experimented with their children’s imminent death while balancing the life they still had, crafting better lives for them. They experimented with a new kind of motherhood: lived in the present tense, focused on daily care, with constant reenvisioning of new ends. By narrating the shared illness experience, they filled the narrative breach and inscribed their children in a narrative world so they could remain here, even when they were gone. These findings suggest that as services often focus exclusively on the child’s well-being, services must also regard caregiver’s needs considering the impact shared illness experiences have on mothers.

### **Development of the Symptom-Focused Health Assessment and Empathy Program: Using an Educational Video for Physical Assessment Among Undergraduate Nursing Students**

Hui-Chen Chen, *Alice Lee Centre for Nursing Studies, National University of Singapore*

Jeanette Ignacio, *Alice Lee Centre for Nursing Studies, National University of Singapore*

Ng Xunlin, *Staff Nurse, Singapore General Hospital*

Piyanee Klainin-Yobas, *Alice Lee Centre for Nursing Studies, National University of Singapore*

This article describes the development of the video component of Symptom-Focused Health Assessment and Empathy Program which includes a symptom-focused case study delivered through self-directed e-learning videos and a simulation-based learning session to enhance the quality of physical assessment. The study is of a qualitative descriptive design. Year 3 and year 4 undergraduate nursing students, nursing faculty, and a clinical expert who have taught a health assessment previously participated to evaluate the video script, storyboard, and content. The research team developed the script, storyboard, and content of the educational video after a review of relevant literature. Two focus group interview sessions, one with students and another with academic staff and an external expert, were then conducted to review the video script and content and to provide feedback for improvement. Both interviews were audio-recorded and transcribed. Content analysis was used for data analysis. The following themes emerged from the students’ focus group interviews: clinical relevance, self-directed learning, educational resources, and video script and content.

Meanwhile, faculty and external expert's focus group interview themes included appropriateness of case scenario, nurse and patient interactions, inclusion of theoretical framework, applicability, and integration into modules. The development of the SHAE physical assessment video will help equip undergraduate nursing students with the necessary competency to assess patients based on sound theoretical knowledge. A video that demonstrates an integrated mode of physical assessment centered on a patient's signs and symptoms will allow effective learning to take place.

### **Using Interaction Analysis of Medical Simulations and Self-Confrontation Interviews to Understand Sensory Work in Telemedicine**

Maria Cherba, *Université de Montréal*

Sylvie Grosjean, *University of Ottawa*

Luc Bonneville, *University of Ottawa*

The use of telemedicine has been increasing to provide care to remote populations, minimize travel costs, and reduce wait times, among others. One particular challenge of patient/provider communication in this context that needs further investigation concerns the sensory dimensions of clinical practice, since providers conduct physical examinations and establish a diagnosis without direct access to a patient's body. The objective of our study, conducted in partnership with the medical simulation centre of a large university-affiliated hospital in Ontario, was to describe how "the sensory work of medical decision-making" is accomplished during videoconferencing consultations. To address the methodological challenge of making sensory work visible, we combined video recordings of consultations with self-confrontation interviews. We recorded 10 postorthopedic surgery visits with a standardized patient accompanied by a nurse. Immediately after each visit, physicians (five surgeons and five residents) watched and commented on their video recordings. Thematic analysis of the interviews revealed two ways of accomplishing sensory work at a distance: the constitution of a diagnostic space by moving the camera and engaging the bodies, and the distribution of embodied practices to sense-at-distance. Video-based interaction analysis of the visits was then conducted to examine these practices in more detail and showed that interactions between the physician, the patient, and the nurse are at the centre of sensory work in telemedicine. Implications of our analyses for developing telemedicine training programs will be discussed.

### **Korean Cancer Survivors' Health Information Seeking Experiences**

Hanna Choi, *Nambu University*

More than 50% of Americans and 60% of Koreans have experience searching for cancer-related health information. For the

above, the internet was the most popular tool, and prior studies have shown that these experiences influence health outcomes such as cancer screenings. In this study, the qualitative research method was used to investigate cancer survivors' health information seeking experiences. Twenty-two cancer survivors living in Seoul participated in interviews conducted in June 2018. The data were analyzed with the qualitative content analysis method, and five main domains and 11 subdomains were derived: (1) Meet the Information King: escaping fear of metastasis and recurrence, finding information, and participating in emotional exchanges in online and off-line communities; (2) Friendly Teacher Beside Me: filling the gap left by busy medical staff and facilitating self-management after discharge; (3) My Little Secretary: being together whenever and wherever and selecting various platforms and channels; (4) Becoming an Expert on Your Own: searching for conviction and avoiding nagging (duplicate information); and (5) Barriers: inconveniences related to entering information, cellular data usage and battery problems, providing personal information. Because more than 90% of Korean adults use the internet in their daily lives, cancer survivors' self-care was also heavily focused on online health information seeking. In addition, personalized information synchronization and alerts, stronger security, and low-capacity health information apps were demanded to overcome obstacles. This study's results may be utilized as baseline data for intervention development and system establishment to promote health among cancer survivors.

### **The Transition From Hospital-to-Home: Caregiver Experiences of a Person With a Life Sustaining Device**

Pamela Combs, *University of Chicago Medical Center*

Anupama Suresh, *College of Medicine, Ohio State University*

The ventricular assist device (VAD), a once rarely used technology, is now frequently employed as a bridge for heart transplantation, destination therapy, or myocardial recovery. Hence, healthcare providers are more likely to encounter the utilization of the device in current clinical practice. Established literature does not evaluate the perspective of the caregiver of a person with a VAD (PWVAD), specifically those caregivers' perspectives in relation to hospital-to-home (HtH) experience. The impact of a PWVAD on the caregiver must be evaluated if holistic care is to be provided. Using Colaizzi's method of analysis, this study explored the caregivers' experiences regarding their HtH transition using phenomenology. The purposive sample consisted of seven caregivers in a rural community. Semistructured interviews were conducted with each person, and data were analyzed concerning perspectives. Procedures recommended by Lincoln and Guba were utilized to confirm trustworthiness. The theme of power permeated the experience of the HtH transition and was determined to be the essence of caregiver experience. The resulting six themes were

described as (1) power of electricity, (2) power of life, (3) power of control, (4) power of super-being, (5) power of change, and (6) power of known and unknown. The knowledge from this study can therefore be used to develop teaching tools and strategies that promote the emotional and physical well-being of caregivers.

### **Exploring Residential Care Aides' Workplace Relationships: Workplace Incivility and Relational Aggression**

Heather Cooke, *University of British Columbia*

Jennifer Baumbusch, *University of British Columbia*

Respectful and collaborative workplace relationships between residential care aides (RCAs; unregulated workers also known as health care aides, personal support workers and nursing assistants) are considered essential for quality care provision in long-term residential care. However, exposure to peer workplace incivility and bullying potentially disrupts such relationships. This article explores the nature of peer incivility in RCAs' workplace relationships and the role of relational aggression in such behaviour. Using critical ethnography, we conducted more than 80 hr of participant observation and 32 semistructured interviews with RCAs, licensed practical nurses, support staff and management in two, nonprofit care homes in British Columbia, Canada. Findings reveal that RCAs encountered peer incivility—covert, subtle, microaggressions with an ambiguous intent to harm—on an almost daily basis. Staff narratives were characterized by three key themes; the first, “it’s just like high school” reflects the school yard behaviour (e.g., gossiping, social exclusion, retaliation, social cliques) experienced by RCAs. The second, “it’s just too many women,” highlights the gendered nature of these workplace relationships, normalizing these behaviours. The third, “it’s just strong personalities,” illustrates the role status, power, and control play in such behaviours. We draw upon relational aggression, a concept more commonly utilized in adolescent female bullying, to further explain and interpret RCAs' experiences of peer workplace incivility. The findings can be used to develop gender-based analysis informed workplace policies and procedures.

### **It's Personal: Using Lived Experience as a Resource in Research**

Meghan Crouch, *University of Waterloo*

This presentation will discuss my experiences as a research assistant on a project investigating the roles and strategies of Return to Work (RTW) coordinators for managing RTW of clients with common mental health (MH) disorders. As an individual with lived experience of mental illness and addiction issues, in this presentation, I will share some of my ongoing reflections on what it has been like navigating

the research process with this embodied knowledge. I will discuss how such personal disclosure has impacted my involvement and role in the research project, working with other members on the research team, as well as engaging with, and interpreting the data. The goal of this presentation is to begin a conversation regarding inherent opportunities and challenges of such disclosure, and how exposing my own “vulnerabilities” created possibilities for analyzing the data. Recognizing that every qualitative researcher is not only critical to, but implicated by, the analysis and interpretation process, this presentation will outline some uncertainties and insights in relation to navigating this interactional process and will touch upon issues of reflexivity, embodiment, and disclosure in practice.

### **“We Don't Want to Be Society's Dirt”: Youths' Experiences Transitioning From Paediatric to Adult Services**

Olivia Cullen, *University of Calgary*

Brooke Allemang, *University of Calgary*

Gina Dimitropoulos, *University of Calgary*

The transition from paediatric to adult services is challenging for youth with complex needs. Youth with intersecting health, mental health, learning, and substance use issues are often receiving support from multiple systems, which can further complicate this transition. This can result in young people being more at risk for adverse outcomes due to limited information sharing, collaboration and communication between systems and services. In an effort to better understand how to support youth with complex needs during this period of transition, a province-wide study was conducted, which included interviews with youth, parents/caregivers, and service providers from the health, mental health, and educational and justice systems. This presentation will focus on results from 38 interviews with youth aged 18–24 in Alberta. Interviews provided key insights into young peoples' experiences with systems and perceptions of barriers, facilitators, and challenges to systems collaboration. The data were analyzed using an inductive approach to thematic analysis. Interview transcripts were coded by three independent analysts to identify prominent themes. Four main themes arose from the data, including transitions to adulthood, systems experiences, youth contradictions, and recommendations for improving collaboration across sectors. Implications for working with youth will be presented. Understanding the lived experiences of young people and engaging them in meaningful research participation can support systems improvement that will have positive impacts on the lives of young people as they transition from adolescent to adult systems of care. Findings from this study support the importance and value of engaging service users in decision making and priority setting.

## **A Constant Paradox: Colorectal Cancer Patients and Family Caregivers Experiences in Managing Health After Cancer Treatment**

Colleen Cuthbert, *University of Calgary*

Janine Farragher, *University of Calgary*

Winson Cheung, *University of Calgary*

The posttreatment phase of cancer is one of adjustment and anxiety for patients and the carers. Little is known about colorectal cancer (CRC) patient's experiences in managing health and preferences for support during this time. To address this, we conducted a qualitative study with CRC patients and their caregivers who had completed treatment within the last 5 years. Data were gathered using focus groups and individual interviews which were recorded and transcribed. Interpretive description was used to guide data analysis and interpretation of results. A total of 22 patients ( $n = 19$ ) and caregivers ( $n = 3$ ) were included. The mean time since diagnosis was 3.2 years. Results of the study revealed that CRC patients and their caregivers experience living within a constant paradox. There were several contributors to the experience of being in this constant paradox including (1) accepting the new as normal, (2) relying on self for managing health but needing support, (3) cancer changes life for the better and the worse, (4) knowing support is available but not knowing how to navigate the system, (5) staying positive amidst negativity, and (6) loss of control and taking control over health. In keeping with interpretive description's emphasis on informing clinical practice, this presentation will highlight the following. Health care providers should recognize that CRC patients have changing and sometimes conflicting experiences after treatment. Their ability to manage their physical and mental health may fluctuate. Providers should understand where the patient is at in the moment and tailor supportive care to meets their needs.

## **Nursing Students and Faculty's Perspectives About How Students Are Learning to Work With Older People**

Sherry Dahlke, *University of Alberta*

Sandra Davidson, *University of Calgary*

Maya R. Kalogirou, *University of Alberta*

Nicholas Swoboda, *University of Alberta*

Scholars have identified gaps in practicing nurses' knowledge about how to care for older people, due in part to nurses not graduating with adequate knowledge to work with older people and student nurses being exposed to practicing nurses who may be demonstrating negative perceptions and practices with older people. In this study, we

utilized a social learning lens to examine nursing students and faculty's perspectives about how students are learning to work with older people to understand where knowledge and learning experiences need to be enhanced. Data from focus groups and interviews with nursing students and faculty was analysed using content and thematic analysis. Themes of (1) gaps in education, (2) perceptions about older people, and (3) preferred career path were developed. The data reveal that educational practices lack a clear emphasis on the unique aspects of older people, how to communicate with an older population and manage behaviours associated with cognitive impairment. Ageist perspectives in society influence and perpetuate how students perceive their first clinical experience (long-term care), what it means to work with older people and their preferred career path. In spite of recognition by faculty of the importance of older person care in nursing practice, cultivation of an appreciation of the diversity and complexity of care needs among older persons was lacking for most students. More emphasis about healthy older people and those across the continuum of care as well as targeted learning activities about working with older people is needed in nursing programs. This presentation will provide a detailed explanation of the three themes and recommendations for how we socialize future students to work with older adults.

## **Strategies to Promote the Mental Well-being of Racialized Immigrant Women in Community-Based Mental Health and Settlement Services**

Fay Mahdiah Dastjerdi, *York University*

Mahdiah Dastjerdi, *York University*

Judith MacDonnell, *York University*

Wangari Tharao, *Women's Health in Women's Hands*

Promoting the health of diverse communities is an important dimension of their inclusion and service providers across sectors aim to support the mental well-being of immigrant women. However, little research identifies barriers that providers face in this everyday work or the range of health promotion strategies they draw on, including strengths-based approaches like activism. The purpose of this community-based research was to understand providers' experiences of promoting the mental well-being of racialized immigrant women. A qualitative design using purposeful sampling and a critical feminist and intersectional lens were used. Nineteen service providers over 18 years of age working in community-based settlement and mental health services in Toronto, Canada, participated in one of the three focus groups about promoting client mental well-being and use of strengths-based tools, including activism. All participants were female, bringing varied educational backgrounds, ethnicity, and work experience; most self-

identified as racialized and indicated they had experiences as immigrant women. Thematic analysis identified current health promotion strategies that include storytelling, social gatherings to share resources and reduce social isolation, and encouraging clients to advocate for human rights and social change. These move beyond traditional biomedical and lifestyle approaches, taking into account structural factors and social determinants of health that shape mental well-being. In order to enhance provider practice and expand provider tools to include activism-based strategies, organizational recommendations include bringing settlement and mental health sectors together to collaborate with racialized immigrant women's communities to develop meaningful resources, programs, and services including education, and workshops and training for providers that link activism to mental well-being.

### **Breaking the Silence: Experiences of Service Providers Who Support Racialized Immigrant Women's Mental Well-being**

Fay Mahdiah Dastjerdi, *York University*

Judith MacDonnell, *York University*

Mahdiah Dastjerdi, *York University*

Nimo Bokore, *Carleton University*

Service providers can play a fundamental role in promoting the mental well-being of racialized populations. Although activism can be a strengths-based strategy to promote the mental well-being of racialized immigrant women, little is known about how providers use such strategies with clients. Our community-based research using a qualitative design and purposeful sampling aimed to understand providers' experiences of promoting the mental well-being of racialized immigrant women. A critical feminist and intersectional lens were applied. Nineteen service providers over 18 years of age, working in community-based settlement and mental health services in Toronto, Canada, and with diverse ethnicities, educational backgrounds, and work experience participated in one of the three focus groups. All participants were female; most self-identified as racialized and indicated they had experiences as immigrant women. Themes emerged about everyday barriers that providers encounter such as frequently changing immigration policies, programs, and supports. An unexpected finding that the participants stress is rarely discussed, is the impact of providing care on providers' own mental well-being, including vicarious trauma from hearing stories of client experiences of upheaval, violence-, and war-related trauma. Providers face tensions as they listen to clients' life stories and hear of the pain that clients experience and often undermining their dignity, humanity, and rights. Providers' strengths and strategies to work within and outside of the

system are shaped by factors such as their understanding of the system, their perspectives advocating for racialized populations, and their personal experiences as racialized immigrant women. Finally, in the context of providers' complex personal and work-related experiences, providers also shared key ideas that speak of their resilience and self-determination.

### **Supporting Caregivers' in Their "Cannabis Conversations" With Youth: An Environmental Scan of Available Resources**

Tania Dearden, *School of Nursing/School of Population and Public Health, University of British Columbia*

Emily Jenkins, *School of Nursing, University of British Columbia*

Liza McGuinness, *School of Nursing, University of British Columbia*

Rebecca Haines-Saah, *Department of Community Health Sciences, University of Calgary*

There is limited data on interventions—beyond the school setting—to address the potential harms of youth cannabis use. Family-based interventions hold promise for reducing self-reported cannabis use amongst teens; however, interventions targeting parents and youth have not been extensively studied. Calls to improve youth drug education recommend a harm reduction approach that extends beyond an emphasis on abstinence. This study involved an environmental scan of online prevention and education resources available to parents, families, and caregivers to facilitate dialogue about cannabis with their teenaged children. A systematic search strategy of the grey literature was developed to mimic the process used by the lay public in identifying resources. Videos, websites, and downloadable PDFs aimed at parent/caregivers to educate their teenaged children about cannabis were analyzed ( $n = 59$ ). The language, content, and tone of these resources were thematically analyzed to determine their potential resonance and impact with diverse family audiences, including examining literacy level, family representation, attention to social determinants of health, and underlying substance use philosophy (i.e., harm reduction or abstinence). Findings indicate that although some harm reduction-based materials exist, the majority remain abstinence based. Further, many challenges related to unrealistic levels of literacy, little sociocultural diversity, and stigmatizing language persist. These findings highlight the need for tailored, evidence-informed public health resources that facilitate meaningful parent/caregiver discussions with youth about cannabis to minimize potential harms.



## **TRACE4Parents: Preventing the Health Harms of Youth Cannabis Use in Contexts of Parental Cannabis Use**

Tania Dearden, *School of Nursing/School of Population and Public Health, University of British Columbia*

Emily Jenkins, *School of Nursing, University of British Columbia*

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Rates of cannabis use in Canada are highest among youth compared to other age groups; however, their use is often not addressed by their parents or caregivers who feel ill-equipped to engage in constructive dialogue about substance use and the associated health risks. In-depth qualitative research that draws attention to the “lived experiences” of youth and their families in regard to problematic substance use has been identified as a priority for public health policy, especially during recent cannabis legalization. This project builds upon three past projects from the TRACE (Teens Report on Adolescent Cannabis) program of research in British Columbia and Alberta over the past decade. In this study, in-depth qualitative interviews with parents/caregivers were conducted to explore their experiences discussing cannabis with their teenaged children and the types of supports they would find helpful to facilitate meaningful dialogue. Preliminary data analysis shows emergent themes that highlight helpful versus unhelpful resources, and the important intersections of cannabis use with lingering stigma, youth mental health, and legal status. In the second phase of this project, participants’ interview data will inform the development of knowledge translation materials aimed at supporting meaningful dialogue between parents and their teenage children. Participants who were interviewed will be invited to assist in developing parent resource materials in conjunction with the TRACE4Parents research team. This participatory approach to knowledge translation will help create more meaningful evidence-informed resources that will assist parents/caregivers and reduce the harms of cannabis in youth.

## **When Allergies Take a Backseat**

Karen A. Dobbin-Williams, *Faculty of Nursing, Memorial University of Newfoundland*

Nancy J. Moules, *Faculty of Nursing, University of Calgary*

Food allergy affects close to 300,000 children less than 18 years old in Canada with dramatic increases seen globally over the last decade. Life-threatening food allergy has no cure. Those affected may have a deadly reaction every time they eat with the only treatment being an injection of epinephrine given within seconds to minutes of eating the allergen. Challenges for

children with these allergies are exclusion, feeling like an inconvenience to others, bullying, and anxiety about their condition. The purpose of this philosophical hermeneutic inquiry was to understand the experiences of mothers of teenaged children with life-threatening food allergies. Seven mothers fitting this criteria were interviewed to uncover new understandings about this experience. Transcription and analysis of interviews in hermeneutic research tradition occurred, as influenced by the philosophical hermeneutics of Hans-Georg Gadamer. Findings revealed that this experience encompasses looking toward the future while looking backwards over life already lived, realizing that allergies can take a backseat to other worries, and learning to let go of the vigilance maintained in earlier years. The focus of this oral presentation is on the interpretation “when allergies take a backseat.” Through the new knowledge gained from this study, recommendations are offered on how nurses can support mothers and families with individuals with life-threatening food allergies as well as suggestions of how other structures in society, such as the school system and medical system, may be supportive to these families in living through these experiences.

## **The Impact of an Emergency Physician Lead on Emergency Department Operations and Patient Safety Measures**

Kathryn Crowder, *University of Calgary and Alberta Health Services*

Elizabeth Domm, *Faculty of Nursing, University of Regina*

Rachel Lipp, *Cumming School of Medicine, University of Calgary*

The emergency physician lead (EPL) role was trialed in two Western Canadian hospital emergency departments (EDs). This role is designed to provide physician leadership to improve ED patient flow and identify and address issues delaying patient access to ED care. ED patient flow is influenced by ED boarding of admitted patients and throughput issues as significant determinants of ED patient access block. These issues can precipitate the potentially dangerous practice of “emergency medical service (EMS) park,” where patients brought to EDs by ambulance are assigned to wait in a waiting area with paramedics for an ED bed. The EPL role profiles a senior emergency physician focused on identifying and initiating emergency investigations and treatments for patients in EMS park, managing ED patient flow by matching patient needs with resources, and attending to situations that slow patient access to ED care. In this 6-month, time series mixed methods study, researchers explored the impacts of implementing the EPLs on ED patient flow as measured by EMS time-to-ED-bed, time-to-physician initial assessment, ED length of stay, and patient safety outcomes. Impacts were also evaluated by surveying ED stakeholders including ED physicians, ED

nurses, EMS professionals, and consultant physicians to elicit feedback about the perceived efficacy of the EPL role in improving ED patient flow and patient safety outcomes. Analysis of multidisciplinary feedback data regarding EPLs revealed themes indicating ED physicians working in the EPL role optimized throughput, improved timeliness of ED patient admissions and discharges, and healthcare providers regarded EPLs as a significant resource.

### **A Research Review: Insights From Registered Nurses Engaged in Clinical Reasoning in Nursing**

Elizabeth Domm, *Faculty of Nursing, University of Regina*

Aisha Siddique, *University of Regina*

Registered nurses (RNs) are believed to engage in clinical reasoning (CR) when providing nursing care in clinical contexts. Higgs and Jensen defined CR as essentially professional problem-solving, while Simmons et al. asserted CR includes use of cognitive processes to analyze information. Nurse educators teach and student nurses learn to use CR in nursing practice. Researchers explore student nurses' newly graduated and expert RNs' use of CR using examinations, simulations, and observations. The purpose of this review was to identify how RNs engage in CR to provide nursing care in hospitals. This presentation offers results of an integrative review of how RNs' engaged in CR using Whittemore and Knafl's integrative review methodology. Following problem identification, current primary research literature was searched using search terms RNs, CR, and hospitals, and the final sample of 11 primary studies was evaluated of the level and quality of evidence using the Johns Hopkins Nursing Evidence-Based Practice Rating Scale©. Analysis of data included categorizing, identifying patterns, and deriving themes in data about how RNs working in hospitals used CR. Themes included how RNs used multifaceted CR when providing nursing care for patients, interactions between RNs' use of CR and individual factors, and interactions between RNs' use of CR and workplace organizational influences. Based on results of this review and insights from RNs, ideas for innovative ways for how RNs use CR in clinical practice and opportunities to enhance RNs engagement in CR are suggested.

### **Outsiders Within: The Lived Experiences of Black Female Nurse Executives**

Daihnia Dunkley, *SUNY Downstate Medical Center*

The underrepresentation of minorities in nursing is well documented. Few Black nurses occupy positions of leadership and even fewer Black female nurses advance to careers as nurse executives. In essence, a Black female nurse in an executive role is a rarity, deserving further inquiry, because of the limited available research about this population. The purpose of the study was to explore the lived experience of being Black and female when

becoming a nurse executive, specifically targeting the nuances of being both a racial and gender minority. The research question was what is the essence of the experience of being Black and female when becoming a nursing executive? Using a hermeneutic phenomenological method, this study explored the experiences of a purposive sample of 10 Black female nurse executives through semistructured telephone interviews. van Manen's approach and Collins's Black Feminist Thought as the theoretical framework guided data analysis. Three themes emerged: (a) living in a constant state of readiness, (b) embracing the responsibility beyond the job description, and (c) overcoming. Participants testified of the psychological dynamics of Black womanness, and the burdens of the intersectionality of race, gender, and class discrimination, while managing the complexities and rigors of a thriving career. Discussing the results of this research will help leaders in nursing, healthcare, and related professions to understand further the experiences of Black female nurses, which will inform national efforts to (a) increase minority representation in healthcare professions and (b) eliminate health disparities among minority racial and ethnic groups.

### **Fruit of a Focused Ethnography: A Resource Tool kit for New Mothers Concerned About Changes in Their Pelvic Floor**

Marlene Egger, *University of Utah*

Lauren Clark, *University of California, Los Angeles*

Ana Sanchez-Birkhead, *University of Utah*

Liliana Martinez, *University of Utah*

When a woman has her first child, she faces changes in her body and shifts in her identity. She begins the task of negotiating and enacting the culturally mediated performance of being a mother and parenting a child. The very private nature of pelvic floor changes in many cultures can pose an obstacle to a woman's making sense-making and taking action-taking. To produce a resource toolkit to assist women with postpartum pelvic floor changes, we conducted a comparative focused ethnography of Mexican American and Euro-American new mothers with altered pelvic floor support based on a standardized clinical exam. We interviewed 60 women between 2 and 22 months after their first vaginal delivery and 17 older women that had joined a prolapse registry. Women described their experiences and cultural understandings of pelvic floor changes, and actions taken congruent with their meaning. Selected interviewees formed a community advisory committee to advise us on preferred types of information valued by postpartum women and ways of communicating effectively. Women reported the value of intergenerational conversations to learn from each other's experience, recognizing that each one's experience may be different. Some asked "I don't feel normal. What are the resources for me?" New mothers wanted skills to prepare for conversations with providers, including how to advocate for themselves when necessary. After

evaluating existing resources, we developed videos for new mothers, in English and Spanish, to enhance women's ability to communicate with medical providers. These will be housed on a nationally available website.

### **Experiences of People With Epilepsy When Disclosing "I Have Epilepsy": A Grounded Theory Study for How2tell**

Naomi Elliott, *Trinity College Dublin*

Agnes Higgins, *Trinity College Dublin*

Sinead Pembroke, *Trinity College Dublin*

In Ireland, nearly 40,000 people have epilepsy. Almost one in three people with epilepsy (PWE) do not feel comfortable telling friends and family that they have epilepsy. More than half are uncomfortable telling their employers and work colleagues. This is a major psychosocial issue, as disclosure to colleagues/friends is necessary to manage possible negative consequences that might occur if PWE have seizures and those around them do not know of their condition or how to help. The How2tell study funded by Epilepsy Ireland and Health Research Board Ireland, aimed to address the issue of how PWE tell (or not). We conducted a grounded theory study aimed at understanding the concerns that adult PWE have about epilepsy disclosure and the strategies used to manage these concerns. We interviewed 49 adults with first-hand experiences of telling people "I have epilepsy" across diverse and everyday life situations. Data analysis revealed core strategies that PWE reported using in the process of disclosing, namely, weighing-up why tell and who needs-to-know, identifying opportunities for telling, constructing the message for the moment of disclosure, tailoring the message for different audience needs (family, friends, children, work), telling to make it "ordinary," and dealing with reactions to disclosure. These findings provided a PWE-informed evidence base, which guided the development of a set of multimedia educational tools. We discuss how these tools can support PWE by empowering them with practical knowledge and helping them to develop effective strategies, so it becomes less challenging to tell others "I have epilepsy."

### **Assessment of the Impact of Education and Training on Sterile Processing Practices in Tanzanian Facilities: A Mixed Methods Study**

Olive Fast, *Mount Royal University*

Faith-Michael Uzoka, *Mount Royal University*

Alexander Cuncannon, *Mount Royal University*

Christina Fast, *Sterile Processing Education Charitable Trust*

**Background:** Inadequate training of healthcare workers responsible for the sterilization of surgical instruments in low-

and middle-income countries compromises the safety of workers and patients alike. **Method:** A mixed methods research study involving 10 hospitals was conducted in Tanzania in 2018. The purpose was to identify the impact of education and training on hospital sterile processing practices. Quantitative data collected included pre- and posttraining assessments of hospital sterile processing practices as well as pre- and post-training participant test scores. Qualitative data collected included participant interviews posttraining. **Results:** Quantitative analysis indicated statistically significant effects of the training based on test results for all hospitals; improvement in test scores were found to be directly related to sterile processing training. Hospital assessments revealed that the largest change involved how instruments were cleaned, resulting in rusted and discoloured instruments appearing new. Analysis of participant interviews identified the following themes: practice changes; challenges in changing practice; resource constraints; personal and professional growth; and workers' increased motivation, confidence, and responsibility. Themes noted less frequently include impact of formalized policy and guidelines, reciprocal relationship and partnership building, and perceived changes in surgical site infection incidence rates. **Conclusions:** Providing education and training in sterile processing practices increased workers' knowledge of best practices, application of knowledge, and awareness of issues to be overcome to decrease risks for healthcare workers and patients alike. Training resulted in significant impact on workers confidence in their knowledge, how they understood their work, and their understanding of the impact their practice had on patient outcomes. To ensure countries align more closely with World Health Organization international standards for surgical safety, increased attention to sterile processing practices and education in low- and middle-income countries is necessary.

### **Social Exclusion in the Suicidality of Gay and Bisexual Men Living With HIV**

Olivier Ferlatte, *Université de Montréal*

John L. Oliffe, *School of Nursing, University of British Columbia*

Henry Wu, *School of Nursing, University of British Columbia*

Gay and bisexual men living with HIV (GBMHIV) are at high risk of suicide; yet the specific mechanisms sustaining this inequity are poorly understood. To address this knowledge gap, we conducted a photovoice study to explore the connections between social exclusion and suicidality among GBMHIV. Twenty-two GBMHIV with a past history of suicidality took photographs to illustrate their experiences with suicidality, narrating them in individual interviews. The photographs and interview transcripts were then analyzed using constant comparison and interpretative descriptive methods. This presentation is focused on sharing the inductively derived findings through three interconnected themes that deconstruct the social exclusion described

by the participants, and the connectedness to their previous suicidality. The first theme, trauma and difference, reflected participants' narratives about the challenges with families and growing up in violent environments that led them to feel excluded early on and fueling their suicidality. The second theme, othering illness, included participant's accounts about how their HIV diagnosis led them to feel disconnected from other gay and bisexual men as they routinely experienced rejection and discrimination. Finally, the third theme, blunting ostracism, refers to participants' struggles with depression and substance use that led them to feel a sense of exclusion from society, heightening their suicidality. In the context where mental illness is highly stigmatized, participants also described how shame and guilt associated with mental illness imposed additional barriers to seeking help, to further disconnect and ostracize. The study findings suggest multiple intervention points and potential strategies for promoting GBMHIV's social connectedness.

### **Facilitators and Barriers to Health Behaviors in a Culturally Insular Population: The Ultra-Orthodox Jewish Women in Israel**

Adi Finkelstein, *Jerusalem College of Technology*

Elisheva Leiter, *Linda Joy Pollin Cardiovascular Wellness Center for Women*

Donna R. Zwas, *Linda Joy Pollin Cardiovascular Wellness Center for Women*

Milka Donchin, *Braun School of Public Health and Community Medicine, Hebrew University; Linda Joy Pollin Cardiovascular Wellness Center for Women*

The ultra-Orthodox Jewish (UOJ) community is a primarily low socioeconomic, culturally insular minority subsect in Israel. Compared with the general population, UOJ women report higher rates of diabetes and overweight, lower physical activity rates, and have lower breast cancer survival rates. The current paper describes the development of the first multicomponent disease prevention intervention with women from an UOJ Hasidic community in Israel using a community-based participatory research approach. Conducting research within a culturally insular sect such as the UOJ population is particularly challenging, given the target population's potential mistrust of external institutions and the need for understanding and consideration of cultural taboos and language sensitivities on the part of researchers. This collaborative, seven-staged development process included organization and community partnerships, key informant interviews ( $N = 5$ ), focus groups (5, including 35 women), questionnaires ( $N = 239$ ), and a steering committee meeting ( $N = 11$ ). Mixed methods analyses identified barriers to engaging in preventive health behaviors and intervention preferences. Most of the barriers identified (financial and time limitations, personal preferences and habits, lack of education/awareness, and family-related obstacles) are

similar to those reported by women from the general population. The cultural aspects of women's role in the home, religious restrictions, and modesty are barriers to engagement in health behaviors such as physical activity and healthy nutrition, similar to women from other insular communities. Utilizing a community-based participatory approach in intervention development provided improved cultural tailoring, potentially serving as a model for additional UOJ communities as well as other difficult to access, low socioeconomic, culturally insular populations.

### **“A Space Where People Get It”: A Methodological Reflection of Arts-Informed Community-Based Participatory Research With Nonbinary Youth**

Ellis Furman, *Wilfrid Laurier University*

This presentation will be a methodological reflection of Bye Binary, a community-based participatory research project (CBPR) that explored nonbinary youths' experiences of identity development, engagement in activism, discrimination, and mental health in Ontario, Canada. The arts-informed method of body mapping was employed in a workshop format to garner the experiences of 10 nonbinary youth (aged 16–25), in conjunction with additional qualitative methods (i.e., individual interviews and reflective notes). Findings suggest that the body-mapping workshop fostered a safe environment that promoted idea generation, affirmation, self-exploration, and connections through a shared identity, thus creating “a space where people get it.” Methodological challenges that arose throughout the process are discussed, including engagement in art as “awkward,” barriers of limited time and funding, participant recruitment, and collaboration and integration. Lastly, author will reflect on their learnings engaging in CBPR and provide insights into how researchers can move forward and apply these methods and processes into their own work engaging in arts-informed research or with nonbinary individuals.

### **Perspectives on Transition From Student to Newly Qualified Nurse (NQN): Views of Students, NQNs, Academics, and Clinical Managers**

Helen Gibson, *University of Hull*

Jane Wray, *University of Hull*

The transition from student to NQN is characterised by “transition shock” in which professional and organizational socialisation occurs. Transition frameworks and support (e.g., preceptorship) are considered central to supporting NQNs during this period, enhancing competence and confidence and reinforcing the “flaky bridge”. The STaR project is a mixed methods study being undertaken in the United Kingdom and funded by the Burdett Trust for Nursing. It aims to explore

successful transition and retention of NQNs. This presentation will share the findings from 32 interviews conducted as part of this project with student nurses (final year, final semester of programme), NQNs (at 1 month poststarting employment), and academics and clinical managers exploring their perspectives on the transition process. Data analysis revealed that the transition from student nurse to NQN is multidimensional and incorporates personal, professional, and organisational domains. The presentation will focus on the person in transition (emotional responses, identity, and managing expectations of self and others), the professional in transition (accountability and the competence—confidence continuum), and the organizational and cultural context in which the transition takes place. Academic and clinical enablers and barriers to successful transition will be shared. There is consensus that a supportive environment during the transition period is important for successful transition. By minimizing the factors that contribute to “transition shock” and learning from new nurses and their educators and managers, we can better understand the transition experience and develop approaches that contribute to the nursing workforce retention.

### **A Qualitative Exploration of Social Media in Educational Practice: A Case Study of an Ontario School of Nursing**

Catherine Giroux, *University of Ottawa*

Katherine Moreau, *University of Ottawa*

Social media involve the use of internet-based tools for communication, collaboration, and information sharing. To achieve required nursing competencies, Ontario Bachelor of Science in Nursing students take a combination of courses and clinical placements. Social media can provide a tool for nursing students, who frequently transition between learning in classroom and clinical contexts, to consolidate their formal and informal learning experiences. Furthermore, many nursing students fall within the millennial generation, meaning that they have grown up with digital tools and already use them to share resources and connect with peers. Despite this technological exposure, many millennials lack the digital literacy to effectively use social media for their learning. We know little about how health professions outside of Medicine use social media in teaching and learning, especially outside the context of the classroom and assignments. I am employing a pragmatic three-phase sequential mixed methods case study approach. In Phase 1, I surveyed nursing students at a small university in northeastern Ontario to understand their use of social media for learning. In Phase 2, I collected digital artifacts by following nursing student social media accounts to see what content they shared relating to nursing education. Finally, in Phase 3, I will conduct semistructured interviews to understand what motivates nursing students' decisions to use social media for learning. I will present qualitative findings from Phases 1 and 2 and preliminary Phase 3 findings. This study will contribute to

conversations regarding teaching and learning, communication and collaboration, and professionalism in nursing education and practice.

### **Help-Seeking Among Mothers and Fathers of Children With Neurodisabilities (ND): The Journey of Ladders and Snakes**

Gina Glidden, *McGill University*

Seeking help to assist them with the daily care of their child is an ongoing quest for mothers and fathers of children with neurodisabilities (ND), who engage within both informal and formal support networks. Although research about help-seeking has been conducted within individuals within other contexts, a theoretical understanding of help-seeking that is specific to mothers and fathers of children with ND and that describes the seeking process, how it is experienced, how roles are established within mother/father coparenting dyads, and how mothers and fathers navigate through/within help-seeking networks, is missing from current knowledge.

In this article, I will present findings from my constructivist grounded theory doctoral research that explored the mechanisms, behaviours, relationships, and engagements of help-seeking mothers and fathers. In-depth, semistructured, individual, interviews were conducted with six coparenting mother/father dyads ( $N = 12$ ) to understand their family context and the types of help sought, personal/structural characteristics of seeking, coparenting seeking, and help-seeking over time. Two main categories evolved. The first describes the experiential journey of help-seeking: the emotional roots of seeking, mothers and fathers as individuals, and as coparenting seekers; engaging in help-seeking decision-making; and taking on roles individually and as coparents. The second describes the Cyclical Process Model of Help-Seeking, the three stages representing the “doing” of help-seeking: identifying the need for help, seeking through all venues, settling back into family routines (with or without help). Implications for mothers and fathers, healthcare professionals, and for policy will be discussed.

### **Photovoice as Action Research: A Qualitative Review**

Saria Lofton, *College of Nursing, University of Illinois at Chicago*

Alexis Grant, *School of Public Health, University of Illinois at Chicago*

Photovoice is a participatory research method that allows participants to use photography to document their experiences, and then dialogue to develop potential solutions, leading to action and community mobilization. Although photovoice is categorized as “action research,” the process between the photovoice project itself and action is unclear. We know that action and community mobilization results from a series of

steps, from action planning and goal setting, to advocacy and implementation. The purpose of this literature review was to understand (1) how photovoice functions as action research, through the lens of action planning; and (2) the ways in which photovoice has prompted community mobilization and led to community-wide change. We searched PubMed, Scopus, PsychINFO, Sociological Abstracts, and Web of Science databases and identified 19 papers that used photovoice, included action planning, and identified community-level outcomes. We found patterns in the multiple ways that implementation takes place in the presence or absence of action plans, ranging from community presentations with key stakeholders to targeted policy changes at specific organizations. Of the 10 papers that specified action plans, there were differences in intentionality of actions, steps taken to catalyze action, and ultimately, changes in a community. Our results suggest that the most successful photovoice projects are those that are intentional in creating action plans and taking steps that mobilize community members towards action. Researchers must consider the potential of photovoice as an action research methodology that can provide a clear, sustainable path towards community-wide changes.

### **Women, ART, and the Criminalization of HIV (WATCH): Developing a Feminist Participatory Approach for Analyzing Arts-Based and Narrative Data**

Saara Greene, *School of Social Work, McMaster University*

Mary Vaccaro, *School of Social Work, McMaster University*

Angela Kaida, *Faculty of Health Sciences, Simon Fraser University*

WATCH is a community and arts-based research study that adapted Body Mapping, a form of art and narrative therapy, research method, and advocacy tool, to explore the impact of the Canadian sexual assault law that criminalizes HIV nondisclosure on women living with HIV. Through Body Mapping, trained facilitators lead participants through a series of exercises and each participant responds using visual art to capture their experiences on a life-sized canvas. Body Maps can be used as data in themselves or supplemented with personal narratives. Body Maps communicate feelings and experiences to raise awareness about political, personal, social, legal, and public health issues. Data were collected with 48 women living with HIV at seven 4-day Body Mapping retreats in Ontario (3), Saskatchewan (2), and British Columbia (2). This included responding to guided visual exercises that focused on the women's understanding and experience of the law, and their participation in sharing circles at the end of each day. This presentation will illustrate our feminist participatory approach to analyzing visual and narrative Body Mapping data as a team of women living with HIV and allied researchers, and our

development of a four-stage analysis process that includes (1) training in visual and narrative analysis, (2) development of linked visual and narrative coding framework, (3) engaging in small provincially- and thematically organized data analysis working groups, and (4) a 4-day participatory analysis retreat. Benefits and challenges of utilizing a participatory approach for analyzing visual and narrative data in community-based research will also be discussed.

### **The Ethical Implications of Digital Health Research**

Katherine Gregory, *CUNY/New York City College of Technology*

The availability of big data for interpreting trends and behavior has permeated all aspects of social and scholarly life. Crowdsourcing has become a standard method for gathering data, and unintended consequences of qualitative data scraping tools lends to issues about possible identifiers and presumed anonymity. As a relatively new setting for qualitative methodologists, the development of guidelines for how to responsibly conduct digital health research with emerging tools that have evolved out of recent technological advancements contribute to this ongoing challenge. This interactive discussion session aims at addressing ethical issues that occur when adopting a qualitative approach to digital health research. Unfortunately, IRB applications only touch upon some of these technological developments. We seek to identify benefits and challenges of participant anonymity and consent, power and positionality of the researcher, and usage of the onslaught of secondary data encroaching on our research expectations. What are the implications for the research process, and ultimately who benefits from it? Beyond IRB compliance, we, as qualitative health research scholars, must self-regulate to determine where the new boundaries exist to protect human subjects and to do no harm in the process.

### **A Case-Study Analysis of Communicable Disease Prevention Interventions Among Healthcare Personnel (HCP) in Israel**

Rachel Gur-Arie, *Department of Health Systems Management, School of Public Health, Ben-Gurion University of the Negev*

Inconsistent communicable disease prevention interventions among healthcare personnel (HCP) speaks to the limits of public health law and policy and the importance of HCP ethical obligations. To what extent each intervention should be implemented is circumstantial and based on disease severity, disease prevalence, vaccination uptake rate, and population. Due to their profession, HCP are at a heightened occupational risk of contracting influenza; tuberculosis (TB); and hepatitis B (HBV) due to their increased exposure to immunocompromised populations like children, the elderly, and those with

chronic disease. Through analyzing communicable disease prevention intervention methods in relation to vaccine uptake among HCP, this project evaluates current policy and suggests improved regulation within an Israeli context. Influenza, TB, and HBV are utilized as case studies for investigating the “spectrum” of communicable disease prevention interventions among HCP. Each disease is unique in its history, vaccine efficacy, vaccine uptake among HCP, and regulation. Taking a case-study approach requires clear and effective comparative methods. Semistructured, open-ended interviews and critical document analysis are chosen as methods to properly execute the case study comparison. The interviews and documents will be analyzed using NVivo software (version 11.3.4). This project outlines the complexity of decision making processes for implementing influenza, TB, and HBV prevention interventions among HCP in Israel. Each disease poses a significant threat for HCP and healthcare settings, yet communicable disease prevention regulation, including vaccine policy, is either inconsistent, not properly upheld, or fragmentary.

### **A Thematic Inquiry Into the Burnout Experience of Australian Solo-Practicing Clinical Psychologists**

Trent Hammond, *University of Sydney*

Burnout is conceptualized as a syndrome that consists of emotional exhaustion, depersonalization, and decreased personal accomplishment. Despite the increased frequency and severity of burnout in the Western world, there is limited published research regarding the experiences of clinical psychologists who have had burnout. This presentation will outline a small group of solo-private practicing clinical psychologists' experiences of burnout in Australia. These psychologists provided rich qualitative data by participating in semi-structured interviews. Thematic analysis was the method used to analyze clinical psychologists' natural accounts of their burnout experiences. Using NVivo, emerging themes were identified through coding “first-order constructs” and then axial code “second-order constructs.” The findings showed that psychologists indicated their roles are demanding and a diverse range of symptoms, including the enduring effects of burnout, mental stress, fatigue, decreased personal accomplishment, negative affect, depersonalization, reduced productivity and motivation, and insomnia. They identified precursors of burnout, including excessive workload and hours of work, life stresses, mismanaged workload, and transference. Clinical psychologists suggested that protective factors of burnout include knowledge and years worked in direct care, and trusting and long-term relationships. They indicated the barriers to overcoming burnout include the fallacy that their clients' expectations and needs are more important than their own, the financial cost of working in private practice, contemporary

knowledge and inadequate education regarding self-care, and time constraints. This presentation will provide psychologists and other health professionals insight regarding the burnout experience and inform professionals of the mental shortcomings of working as a solo-practicing clinical psychologist. Findings should lead to an increased understanding of the complexities of burnout and ultimately reduced cases of burnout, absenteeism, and staff disengagement.

### **“The Biggest Decision I’ve Ever Made”: A Grounded Theory of Decision Making Regarding Antidepressant Use in Pregnancy**

Catriona Hippman, *University of British Columbia*

Deirdre Ryan, *University of British Columbia*

Lynda G. Balneaves, *University of Manitoba*

Jehannine Austin, *University of British Columbia*

Depression during pregnancy affects upwards of 10–15% of women. Practice guidelines recommend that clinicians support women to make informed treatment decisions in light of risks of untreated depression and antidepressant use during pregnancy. However, there is minimal evidence regarding how women make these decisions or how clinicians can best support their decision making. This study aimed to develop a constructivist grounded theory, within a feminist theoretical framework, of women's decision making regarding depression treatment during pregnancy. Semistructured interviews were conducted with purposively sampled, pregnant, or preconception women from the community or specialty clinics in Vancouver, BC ( $N = 31$ ). Iterative data collection and analysis, along with theoretical sampling and member checking, were used to determine saturation in the model. Participants were highly conscious of societal stigma towards mental illness and medication use during pregnancy. As a result, they faced fear, anxiety, and guilt while decision making. Participants navigated, in a non-linear manner, between three clusters of decision-making activities: seeking information, making sense of information, and self-soothing. “Seeking information” included internal processes (e.g., reviewing past experiences) and external processes (e.g., seeking healthcare providers' expertise). In “making sense of information,” participants appraised available evidence (e.g., based on trust or their beliefs and values). In “self-soothing,” participants engaged in coping strategies, such as developing mantras or normalizing, to try to alleviate the painful emotions they encountered. This grounded theory can be used by clinicians and patients to support patient-oriented decision making regarding how best to care for maternal mental health during pregnancy.

## **Paramedic Attitudes and Perceptions About Continuing Professional Development in Australasia**

Lisa Hobbs, *Queensland University of Technology*

Scott Devenish, *Queensland University of Technology*

Vivienne Tippet, *Queensland University of Technology*

David Long, *Queensland University of Technology*

This study examined the attitudes and perceptions towards continuous professional development (CPD) of Australasian paramedics working in private and state or territory ambulance services. For the purpose of the study, CPD is described as commitment to both formal and informal life-long learning (LLL) opportunities which are linked to clinical advancements, practitioner competence, professionalism, and the delivery of gold standard patient care. Constructivist grounded theory was used as the methodological framework for this study. Study participants ( $n = 10$ ) completed their paramedic qualification through two main pathways, namely a postemployment in-house Vocational Education and Training (VET) diploma or a preemployment university degree and had worked as a paramedic for a minimum of 2 years. Ethical approval was obtained from the Queensland University of Technology, and the participants signed consent forms prior to participating in the study. Data were collected by semistructured interviews, which were recorded digitally for transcription and analysis purposes. The study found there was not a considerable step up for paramedics to engage in CPD and LLL, as this was already expected prior to professional registration for paramedics commencing late 2018. Some older paramedics expressed fear about keeping up to date with new technologies and a shift in the paramilitary paramedic culture was identified, where education is forming a new hierarchical stigmatisation. A framework of paramedic CPD has been created from the study's findings and builds on the extant literature. The framework acknowledges professional, industrial, social, personal, political, organisational, and economic factors which influence or change engagement in CPD.

## **Tension Between Medical Care and a Sense of Home: Distress in the Chronically Critically Ill**

Fuchsia Howard, *University of British Columbia*

Sarah Crowe, *Fraser Health, University of British Columbia*

Gregory Haljan, *Fraser Health, University of British Columbia*

Chronically critically ill individuals experience a constellation of complex physiological disturbances requiring prolonged mechanical ventilation, with a growing number living in residential care facilities. Yet, there is limited understanding of their unique challenges, knowledge of which is vital to developing

patient-centred interventions. The research purpose was to examine the sources of distress for chronically critically ill individuals in residential care. In this interpretive description, we conducted semistructured interviews with 6 residents, 14 family, and 19 health care providers (HCPs; 39 total). With the aim of centering our findings on the resident and family data, we developed our analytic frame by inductively coding these data and using comparative methods to identify commonalities and differences among these individuals. We then extended identified themes by comparing HCP accounts to those of residents and family. Rather than discuss physical symptoms, resident distress was connected to feeling as though they were patients receiving medical care as opposed to individuals living in their home. The accounts of residents, family, and HCPs suggest that the tension between medical care and a sense of home was related to (1) the prioritization of physical care at the expense of other care needs, (2) feeling dependent on others but neglected at times, (3) limited choice and participation in decision making, and (4) deep sadness and loneliness but limited psychosocial support. Efforts to develop healthcare services for the chronically critically ill must foster a sense of home, wherein individual priorities are valued, decisions are shared, and emotional well-being is central.

## **Integrating Indigenous Worldviews Into a Community Arts-Based Research Project With Women Living With HIV Across Canada**

Valerie Nicholson, *Simon Fraser University*

Allyson Ion, *McMaster University*

Women, ART, and the Criminalization of HIV (WATCH) is a community arts-based study that engaged Body Mapping to explore how the criminalization of HIV nondisclosure impacts the lives of women living with HIV in Canada. Women from British Columbia, Saskatchewan, Manitoba, and Ontario took part in workshops to create Body Maps by sketching and painting symbols and words in response to creative exercises. Our team of women living with HIV, academic researchers, and community activists conducted a participatory analysis process to explore the images and narratives that participants shared during the workshops. This presentation will focus on our team's journey to integrate Indigenous approaches into all aspects of the research. Because of the leadership of Indigenous women living with HIV on the research team, and 60% of participants identifying as Indigenous, our team made decisions during the planning, team training, workshop implementation, and participatory analysis processes to ensure that the study acknowledged and was responsive to Indigenous ways of knowing and the particular experiences of Indigenous women living with HIV in Canada. This presentation will discuss (i) applying the Body Mapping methodology in research focused on women and the criminalization of HIV nondisclosure; (ii) the leadership of Indigenous team members and elders who facilitated the integration of traditional teachings and ceremonies in the training, participant workshops, and analytic



processes; (iii) incorporating Indigenous worldviews in our interpretation and mobilization of findings; and (iv) how our team-based approach facilitated two-eyed seeing and honouring of Indigenous worldviews by Indigenous and non-Indigenous team members.

## Using Institutional Ethnography to Explicate the Social Organization of Perinatal Care for Women Living With HIV in Ontario

Allyson Ion, *McMaster University*

Through my affiliations with research projects focused on women and HIV, I have come to learn about the challenges that women living with HIV encounter when interacting with health-care as pregnant women and mothers. Some qualitative research has highlighted women's narrative accounts during the perinatal period; no research has connected women's perinatal care experiences to institutional arrangements such as organizational work processes and regimes of governance. I saw an opportunity to make visible how women's experiences are produced in the routine operation of perinatal health services. My doctoral research began from the standpoint of pregnant women and mothers living with HIV. I chose institutional ethnography as my method of inquiry to trace the connections between women's experiences, the activities of healthcare providers, and the ruling relations that organize women's experiences and healthcare providers' activities. Moving beyond an abstracted theorization of women's experiences, I examined how women's concerns are organized by ruling relations including institutional policies and ideological discourses that underpin the work practices of healthcare providers (e.g., risk, fear of contagion, AIDS hysteria) and that create the conditions for the kinds of experiences that women living with HIV expressed. This presentation will (i) outline the rationale and motivation for using institutional ethnography for doctoral health research, (ii) discuss what was revealed through my inquiry, and (iii) discuss the utility of institutional ethnography to direct action and organizational change in ways that amplify women's voices and experiences and that promote justice-oriented healthcare practice.

## "It's Not Your Fault That You Break Down"—A Study of Self-Blame in Newly Graduated Nurses in Medical Units in Denmark

Carsten Juul Jensen, *University College Absalon*

**Introduction:** Based on results from an institutional ethnographic investigation, I here describe results of studies of self-blame of newly graduated nurses' within the individualism of contemporary society. **Method:** Following the institutional ethnographic approach, the data consisted of interviews and participant observation at four medical units of five newly graduated nurses as well as less intensive observations of 20 clinicians from an interdisciplinary health team. These data are

complemented by analyzes of political documents on financial agreements between the state and the regions in Denmark as well as national goals of the Danish health care system developed by the Danish Institute for Quality and Accreditation in health care. **Results:** The medical units in this study treated elderly patients with comorbidities. Newly educated nurses express shock, loneliness, anxiety, and feelings of guilt and self-blame related to unfinished work tasks and low performance, due to lack of experience. Moreover, they lived in constant fear of harming patients fatally or being blamed for patients' death. The intensity of self-blame is worse in the youngest, female newly graduated nurses. These young women appear overly responsible and conscientious in their effort to handle nursing care in medical units under the given work conditions and the actual political control mechanisms. Individual responsibility is imposed on newly educated nurses by the political ideologies embedded in New Public Management (NPM), where the health care professional is individually responsible for completion of activities and for identification of patients' risks of developing fatal diseases in the most economically effective way possible. **Discussion:** Treatments and care of patients at medical units rarely correspond to goals of economy and quality assurance within NPM. In contemporary society, newly graduated nurses are supposed to be individually responsible for their own success but at the same time are held responsible for the lack of opportunities to perform successfully in a medical unit where patients are both chronically and acutely ill. **Conclusion:** Newly graduated nurses responded with self-blame when they encountered politically controlled realities in medical units. This self-blame is intensified by NPM, which stresses that health professionals are individually responsible for delivering health for the least amount of money.

## Newly Graduated Nurses' Experiences With Death and Dying Patients in Medical Units at Patient Safety Hospitals in Denmark

Carsten Juul Jensen, *University College Absalon*

**Introduction:** Here I describe an investigation of newly graduated nurses' challenges associated with the ideology of survival and "the good death" in medical units at patient safety hospitals. **Method:** I used an institutional ethnography approach. Data sources included participant observations on medical units, interviews with newly graduated nurses and coworkers who worked on these units, and documents related to the Danish patient safety program. Data were analyzed by examining the speech and behavior of participants. **Results:** The medical units on which the study was conducted treated elderly patients with comorbidities. Many patients died during hospitalization. The newly graduated nurses verbalize their work with death and dying patient in terms of "I am afraid of killing patients" or "I kill patients." Danish patient safety programs in medical units describe goals of healthiness, survival, and productivity. Hence, the majority of work activities are related to survival of patients. Doctors inspect unintended deaths and health care staff identify

critical illness using various “early warning” tools. However, doctors disclaim responsibility for a patient’s death if they are incurably ill. If survival is no longer possible, the doctors entrust nurses to define and secure palliative care. **Discussion:** Due to the work required to care for complex medical patients, newly graduated nurses find it difficult to address time-consuming tasks of organizing and providing palliative care that results in “a good death,” with comfort for patients and their relatives. Newly graduated nurses verbalize their work with death and dying patients as murder due to patient safety programs and the program ideologies of healthiness, survival, and productivity. **Conclusion:** Newly graduated nurses are unaccustomed to working with death and dying patients and may consider themselves as failed nurses if patients die in patient safety hospitals where death could be perceived as a mistake.

### **Evolving Roles and Responsibilities After the Legalization of Medical Assistance in Dying: Interprofessional Palliative Hospice Care Professionals’ experience**

Soodabeh Joolaei, *Iran University of Medical Sciences; Center for Health Evaluation and Outcome Sciences (CHÉOS); Nursing Care Research Center, Iran University of Medical Sciences*

Anita Ho, *Centre for Applied Ethics, University of British Columbia; UCSF Bioethics; Centre for Health Evaluation and Outcome Sciences (CHÉOS)*

Christopher Ng, *University of British Columbia*

Legalization of Medical Assistance in Dying (MAiD) in Canada represents a fundamental change in both the scope and philosophy of end-of-life (EOL) care. This is particularly the case for palliative/hospice care professionals (PHCPs) at the forefront of EOL care. We conducted 26 semi-structured interviews with interprofessional PHCPs in Vancouver, Canada, to elicit their experience in caring for patients who inquired about or requested MAiD. The transcribed interviews underwent qualitative content analysis. This presentation focuses on PHCPs’ experience of changes in their roles and responsibilities in providing EOL care in the new era. Participants in both frontline and administrative roles explained their expanding formal and informal responsibilities, which directly impacted their workload. For PHCPs who provide frontline direct care, preparing and training themselves for the MAiD practice, having difficult conversations with patients and families juxtaposing MAiD versus traditional EOL care options, and also being present throughout the process supporting patients and families were considered expanded roles and responsibilities. For administrators, coordinating the MAiD logistics as well as debriefing and supporting the team were new responsibilities that increased their workload significantly. Participants highlighted how the different moral dimensions brought on by MAiD require more time and emotional energy and can impose heavy

moral weights on PHCPs both in their professional and personal lives. Based on the findings, we provide recommendations to support not only patients and families in this new legal landscape but also to support staff and prevent burnout as they navigate their evolving roles and responsibilities.

### **Beyond Hospital and Medical Care: Social Determinants of Pregnancy and Birth Outcomes of Women living in Remote Mountain Villages in Nepal**

Sabitra Kaphle, *Central Queensland University*

The main objective of this article is to highlight the impact and significance of social determinants of health on women’s childbirth experiences and birth outcomes in the context of remote mountain villages of Nepal. This study used a qualitative approach guided by the principles of social constructionist and feminist critical theories to derive factors influencing women’s experiences of pregnancy and childbirth. This study was conducted in two remote Nepalese mountain villages drawing on the pregnancy and childbirth experiences of women with high rates of illiteracy, poverty, disadvantage, maternal and newborn mortality, and low life expectancy. Twenty-five pregnant and postnatal women, five husbands, five mothers-in-law, one father-in-law, five service providers, and five local community stakeholders participated in interviews. The findings of this study suggest that the access to pregnancy and childbirth services in remote mountain villages of Nepal has been influenced by key social determinants of poverty and food insecurity, education and illiteracy, women’s domestic roles, politics, and local governance; these are all critical to promoting maternal and newborn survival. This study highlights a need to apply a social determinants approach to address the barriers that are limiting women’s access to care during pregnancy and childbirth in remote settings. The findings urge for an immediate shifting of policy from the medical service approach to a social determinants approach to promote improved maternal and newborn health outcomes in remote mountain villages of Nepal.

### **Older Women’s Narrative Strategies of Resistance Told in “Small Stories”**

Makie Kawabata, *Kansai University of International Studies*

This study explores resistance strategies used by older people, using their own stories and applying positioning analysis, which focuses on “naturally occurring conversation” rather than the autobiographical model. Twenty-one older women living independently were interviewed. We use their stories to illustrate their strategies for resisting the dominant view that aging means decline and dependence in later life. The three women, through their stories, showed contradictions between their struggles with the dominant view that seeks to deprive them of the right to

continue meaningful independent lives and their recognition of the reality that they are becoming increasingly dependent. In order to reconcile the contradictions, they tried to construct resistance narratives using innocuous strategies while maintaining dependence on others in their declining stages. Accordingly, their resistance was not apparent in their rhetoric but became clear when using positioning analysis to disentangle and reconstruct the complexities of their narratives. The author suggests that aging studies should pay more attention to everyday conversations and their local contexts to understand older people's resistance and to incorporate their perspectives into public policies in order to create a counter-discourse of "meaningful decline and dependence."

### **Knowledge Mobilisation in Decision Making by Advanced Nurse Practitioners in the Emergency Department: An Ethnographic Study**

Rachel King, *University of Sheffield*

Tom Sanders, *University of Northumbria*

Angela Tod, *University of Sheffield*

Emergency departments (EDs) in the United Kingdom (UK) are under increasing pressure due to waiting time targets, the aging population, and workforce shortages. One solution is the introduction of advanced nurse practitioners (ANPs), a role plagued by ambiguity of scope of practice, education, and regulation. Little is known about how ANPs manage the knowledge gaps emerging from their advanced role. Knowledge mobilisation (KM) research is concerned with reducing the theory–practice gap. The aim of this study was to explore how knowledge is produced, shared, and accessed in ANP discharge decision making.

An ethnographic study was undertaken in an ED in the North of England between September 2016 and July 2017. Data collection involved observation of ANPs ( $n = 5$ ) and interviews with ANPs and senior clinicians ( $n = 13$ ). Field notes and interview transcripts were managed using Quirkos software and analysed thematically. Data from the observations were triangulated with interview data and added to the rigour of the findings. Findings reveal differences between stakeholders in the drivers for role development. Boundary blurring was characterised by role ambiguity and knowledge gaps. Knowledge mobilisation was messy and complex, illustrated by the wide variety of knowledge sources accessed and preference for shortcuts to knowledge. ANPs valued opportunities for "situated learning" from medical colleagues, peers, and through clinical experience. The findings have implications for policy and practice in preparing ANPs for autonomous decision making. Role clarity and consensus are crucial in managing boundary blurring in addition to access to situated learning and shortcuts.

### **An Exploratory Study of the Motivations, Experiences, and Career Aspirations of Trainee Nursing Associates in the North of England**

Rachel King, *University of Sheffield*

Steve Robertson, *University of Sheffield*

Emily Wood, *University of Sheffield*

Tony Ryan, *University of Sheffield*

The nursing associate (NA) role has recently been introduced in England following a major policy review of the training and education of health care assistants (HCAs) and registered nurses (RNs). The role aims to fill the perceived gap between HCAs and RNs and to provide an alternative route into nursing in light of national workforce shortages. There is currently a shortfall of 40,000 nurses in England. Globally, HCAs and support workers lack training opportunities. Little is known about the trainee nursing associate (TNA) role, and this study aimed to explore the motivations, experiences, and career aspirations of TNAs. Three focus groups ( $n = 15$ ) were undertaken in December 2018 using a purposive sample of TNAs registered at a University in the North of England. This method is particularly useful in generating data through group interaction which progresses back and forwards. Two researchers facilitated each group which lasted between 42 and 60 min. Focus group discussions were audio recorded, transcribed, and analysed thematically. Quirkos software was used to manage the data. The findings reveal that TNAs experience personal growth through affordable local career development opportunities. They face challenges relating to clinical placements and academic pressures. TNAs experience personal and organisational role ambiguity and value naturally occurring communities of practice in building occupational identity. Findings from this study will inform strategies to support the development of nursing associates and other emerging roles in healthcare. It has informed the design of a longitudinal cohort study of TNAs. The discussion will include lessons from this study which may be relevant to wider international health-care contexts.

### **Reimagining the Three Delays Framework for the SDG Era: A Qualitative Analysis of Maternal Deaths in Rural Pakistan**

Mai-Lei Woo Kinshella, *Department of Obstetrics and Gynaecology and BC Children's Hospital Research Institute, University of British Columbia*

Sana Sheikh, *Centre of Excellence, Division of Women and Child Health, Aga Khan University*

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**Sumedha Sharma, Department of Obstetrics and Gynaecology and BC Children's Hospital Research Institute, University of British Columbia**

Pakistan has one of the highest maternal mortality ratios in the world (348.6/100,000 live births). This analysis explores the social and systemic factors that contributed to maternal deaths in rural Sindh, Pakistan, using 54 narratives associated with verbal autopsies during the Community Level Interventions for Pre-eclampsia (CLIP) Pakistan Trial (NCT01911494) between 2014 and 2017. The Three Delays Framework helped galvanize momentum to reduce global rates of maternal mortality leading up to and during the Millennium Development Goals, but a deep exploration of the theory reveals four potentially problematic assumptions: (1) women are giving birth at home, (2) all pregnant woman are at risk of death, (3) deaths are due to direct causes, and (4) time is the key determinant to reducing maternal deaths. Qualitative analysis of the verbal autopsy narratives of maternal deaths in rural Pakistan reveals an interplay of various themes in determining maternal health outcomes such as underlying maternal health risks, temporary improvement in health status after seeking care, quality of care in critical situations, convoluted referral systems, and arrival at the final facility in critical condition. Evaluation of these narratives helps to reimagine the pathways of maternal mortality beyond a single journey of care-seeking; to breakdown the rigid categories of seeking, reaching, and receiving care; and to argue for the potential of prevention and early management and the need for functioning health systems. In the era of the Sustainable Development Goals, there is a need to reimagine the Three Delays Framework to highlight the inequalities of risk and complexity of these pathways.

**Involuntary and Coercive Psychiatric Treatment: A Critical Discourse Analysis of British Columbia's Mental Health Act**

**Marina Kolar, School of Nursing, University of British Columbia**

British Columbia's Mental Health Act (MHA) is a piece of legislation mandating involuntary treatment of people experiencing mental health issues who are unwilling to receive treatment on a voluntary basis. Utilizing Fairclough's Dialectical-Relational Critical Discourse Analysis, this thesis analyzes how the MHA and a companion document, the Guide to the Mental Health Act, structures practices of overriding usual requirements for consent to care and removes self-determination for people deemed in need of involuntary treatment. Findings illustrate how the Act and Guide are constructed within socio-historic discourses of biomedicalism, psychiatry, ableism, colonization, marginalization, and neoliberal orientations of governments. These discourses delineate a boundary between "normal" or acceptable behaviour and "abnormal" or unacceptable behaviour deemed in need of correction through psychiatric treatment. The Act and Guide constitute involuntary service users as patients with "mental disorders" who are too vulnerable

or dangerous to care for themselves and therefore in need of protection from themselves and others. These texts align "mental disorders" with incompetence and incapacity, justifying the need for protection. Involuntary and coercive treatment practices authorized by the Act are implemented by nurses, physicians, and police officers. The manner in which the Act and Guide construct patients and protection highlights how discourse operates to produce and maintain dominant social relationships beyond the clinical setting. Thus, the discourses of the Act can be seen as produced within the project of governing and as being central to the maintenance of the social order. Although the MHA's stated intentions are to reduce harm and provide care for people experiencing mental health issues, this analysis illustrates how discourses employed by these texts participate in the violation of safety and consent of the people it intends to serve—commonly disadvantaging those already experiencing social and economic marginalization. Current health care practices and structures that rely on harmful narratives and discourses based on deficit, vulnerability, dangerousness, and incapacity can be countered by employing discourses of equity. Nurses are ideally positioned to challenge discourses and practices that compromise people with mental health issues' human rights, entrenching social inequity.

**Staying Connected: Consumer Experience of the Recovery Journey and Long-Term Engagement With a Rural Mental Health Clinic**

**Eric Howey, Alberta Health Services**

**Lyuda Krupin, Alberta Health Services**

**Tara Perry, Alberta Health Services**

**Nick Todd, Alberta Health Services**

While there has been much interest in recent years about the potential impact short-term therapy can have on those needing mental health support, relatively little attention has been paid to the needs of those who require longer term support. In an ethnographic study that incorporates a participatory action research (PAR) design, exploring long-term clients' experiences of the recovery journey and the role of rural mental health support in facilitating that journey, a sample of six ( $n = 6$ ) consumers who had a minimum of 5 years of continuous involvement with a community-based mental health clinic participated in a series of two focus groups. The first focus group examined consumers' experiences of the recovery journey and the role of the clinic in supporting their journey. The second focus group involved a member check that allowed for participant feedback on the researchers' summary of themes that arose from the first session. In this way, participants were given voice in revising and shaping the thematic analysis to share their lived experiences of illness, recovery, and resilience. Emerging findings demonstrate how the journeys shared highlight themes of contending with extreme violence, the

importance of accessible ongoing support, and finding a reason to go on in the wake of devastating personal experiences. Implications of these findings and recommendations for next steps will be discussed.

### **Ko Ngā Kaumātua Ō Tātou Taonga: Supporting the Well-being of Māori Elders in a Changing World**

Hilary Lapsley, *University of Auckland*

Marama Muru-Lanning, *University of Auckland*

Tia Dawes, *University of Auckland*

Health indicators for older Māori reflect persistent inequities in Aotearoa/New Zealand, yet the well-being of kaumātua (elders) appears robust. It is possible that their crucial role in transmitting traditional knowledge and practices may sustain well-being through strong social networks and a sense of purpose and value. Our programme of qualitative research aims to highlight kaumātua voices in the search for pathways towards fostering well-being and remediating health inequities. For a feasibility study, our seven-member team (Māori, with one exception) met with kaumātua from two localities to plan noho wānanga, intensive meetings to exchange knowledge and ideas. The wānanga, held over a 24-hr period, involved focus group-style sessions, interviews in pairs, and shared meals. Kaumātua appreciated the opportunity to talk about ageing well, and the study demonstrated that our innovative approach sits well amongst the tools of kaupapa Māori methodology (research methods designed by and for Māori). The data were analysed with NVivo, showing that kaumātua understood health and well-being holistically and historically, showed less interest in their own health than we expected, and were dedicated to their roles and to the well-being of their communities. With a further grant, we explore community responsibility for kaumātua health and well-being. We add oral history techniques to our palette, and we broaden the investigation to include family, community, and health services. As well, we strongly emphasize place in its historical, geographical, and social context, echoing kaumātua voices from the initial study.

### **Personal Phenomenology: An Innovative Methodological Approach That Brings the Person and the Ethical Call at the Core of Research Practices**

Mihaela Launeanu, *Trinity Western University*

Although in health research we study human beings in a variety of contexts and life situations, the present methodologies that aim to explore these participants' experiences tend to miss a direct engagement with their person and, subsequently, with the inherent ethical dimensions of the human phenomena that we investigate. Although we operate under the tacit assumption that because we study human beings we are implicitly

conducting personal research, most current research methodologies are not well prepared to explicitly investigate the personal and ethical dimensions of participants' experiences beyond emotionality and the associated meanings. The personal phenomenological methodology acknowledges its philosophical moorings at the intersection of two traditions: the lineage of the existential phenomenology and philosophical hermeneutics, and that of the European personalism. The personal dimension is constitutive to a phenomenological view since human beings exist not only as bearers of the disclosures of being but as ethical, communal persons. Understanding the person as an "ethical being-to-and-for-the-other," personal phenomenology brings to the fore the relevance of the ethical call, social justice, and personal encounter amidst embodied alterities at the core of research practices and provides an existentially grounded response to the impetus for social justice and multicultural awareness as core values of contemporary research ethos. This article will present the core tenets and method of personal phenomenology. Examples from empirical research will illustrate how personal phenomenology could be enacted in our research practices as innovative research methodology that brings the ethical, personal dimensions at core of our practices.

### **The Experience of Older Adults in a Socio- Ecological Behavioural-Based Physical Activity Intervention Developed by Community-Based Participatory Research Approach in a Low-Income Neighbourhood in Hong Kong**

Lok Chun Janet Lee, *University of Hong Kong*

Rainbow Tin Hung HO, *University of Hong Kong*

**Background:** With the ageing-in-place policy as the backdrop and the recognition of social-ecological model in physical activity (PA) intervention, increasing number of PA intervention studies among older adults have been based on the social-ecological behavioral model. Among these studies, very few of them used community-based participatory research approach (CBPR) to develop the intervention. **Objectives:** This study aims to explore and analyse the experience of older adult participants in a 5-week PA intervention developed by CBPR. **Methods:** An individual semi-structured in-depth interview ( $n = 42$ ) was used to assess the experience and impacts of the intervention in changing PA behaviour and attitude. The ecological framework was used to define the structure for data organization. Thematic analysis of the data was performed. **Results:** Findings revealed that at the environmental level, the intervention improved participants' understanding and utilization of public outdoor exercise facilities (OFE), and utilization of resources in the immediate environment allow convenient and easy implementation. At social level, exercising in the neighbourhood public area made participants feel socially supported by neighbours. At individual level, there were increase

in exercise-efficacy and health improvements. **Conclusion:** The findings from this study provide overall support for the intervention and inform the design and implementation of a definitive interventional trial in the future.

### **“Think About the Imagined Robot That Can Assist you”: The Use of Exploratory Art-Based Research Methodology With Community-Dwelling Older Adults to Understand Their Perspectives on Assistive Robotic Device**

Lok Chun Janet Lee, *University of Hong Kong*

**Background:** Growing amount of attention is given to the developments of robotic device (RD) to support for community-dwelling older adults. Most previous research explored older adults’ perspectives on robotic device based on interviews after users’ experience test. To date, very few researches in gerontological technology used creative form of methodology to elicit older adult’s prospective on RD, and less research asked older adults’ view on the design outlook of the robot. **Methods:** Exploratory art-based methods (draw and tell) were used to collect data from a convenience sample of 16 older adults ages 62–93 in a Neighbourhood Elderly Centre in Hong Kong. The drawings were analysed using thematic analysis. **Results:** 2 of 16 older adults fail to envision the function of their imagined robot after the drawing task. While most older adults felt that the drawing task was challenging in the beginning, they can eventually draw the robot in a group-based interactive atmosphere. Regarding the functions of their imagined robot, five themes emerged, they are (1) housework, (2) companionship, (3) support disability, (4) logistic support, and (5) get them out of home. Regarding the location of usage, three themes emerged, they are (1) home, (2) public, and (3) institution. **Conclusion:** Most findings are in line with the direction of current development of robotic device. Unlike current development of robotic device which primarily focus on home use, the older adults in this sample also pointed out they would like to have robot helping or entertaining them in public locations.

### **Digital Storytelling and Qualitative Learning**

Maya Lefkovich, *University of British Columbia*

It is an exciting time to be a qualitative researcher! With increasing opportunities to draw on arts and integrative knowledge translation (IKT) in our work, we are pushing the boundaries of qualitative health research. As such, we must be critical about the purpose and potential impact of this methodological innovation. As qualitative researchers, how are we adapting, reflecting on, and taking responsibility for our ever-changing practices? And for whose benefit? As an interdisciplinary PhD candidate, I developed, piloted, and reflected on an emerging methodology for collaborative digital storytelling as my dissertation. With careful attention paid to issues of authenticity,

collaboration/solidarity, and aesthetics, I blended practices, principles, and ethical frameworks from qualitative, Indigenous, arts-based, and journalistic methods. But, as I discovered, synergies between different methods in theory do not always translate in practice. Navigating methodological tensions in the cocreation of digital stories challenged many of my unquestioned assumptions, trainings, and priorities as a qualitative health researcher. In this oral presentation, I explore how qualitative researchers can be both reflexive and adaptive in light of the growing pressure to jump on IKT and arts-based trends. Starting from an anti-racist and feminist foundation, I use digital storytelling to illustrate when my qualitative training helped and hindered my ability to work creatively and in solidarity with stakeholders. Acting on values of reflexivity and accountability, I will offer key questions and strategies from arts-based research and IKT to help us grapple with future directions of qualitative methods and health research as a group.

### **Relational Ethics of the Nurse’s Touch in the Neonatal Intensive Care Unit**

Gillian Lemermeier, *Faculty of Nursing, University of Alberta*

When we talk about healthcare ethics, we tend to think about deciding what is the right or wrong thing to do. Ethics in health care can also be found in the moments that nurses, physicians, and other healthcare professionals spend with patients and their families. Whether we speak of moments such as placing a newborn child into their parent’s arms for the first time or soothing a distraught, disoriented adult, all such caring encounters reveal ethics. And of course, few require a more delicate, nuanced, and expert touch than those unfolding in the neonatal intensive care unit (NICU). Drawing on observations and interviews with NICU nurses, this research project attends to the relational ethics of healthcare practice by considering a specific experience: the relational encounter of nurse with baby in the NICU. The goal of this study is to better understand the possible meanings of the nurse’s touch of babies and parents from a relational ethics perspective. This project uses phenomenological human science research methods helpful for understanding the taken-for-granted aspects of our daily lives and professional practice. A phenomenological understanding of nursing touch should help develop ethical sensitivities of practitioners.

### **Perception of Pregnancy Risk Among Women With Gestational Diabetes and Their Partners: Qualitative Findings**

Suzanne Lennon, *University of Manitoba*

Maureen Heaman, *Rady Faculty of Health Sciences, University of Manitoba*

Roberta Woodgate, *Rady Faculty of Health Sciences, University of Manitoba*

Catherine Cook, *Rady Faculty of Health Sciences, University of Manitoba*

**Background:** Gestational diabetes (GD) is a common complication of pregnancy, yet little is known regarding how women with GD perceive risk during pregnancy. No studies have been conducted regarding the partner's risk perception. The study purpose was threefold: (1) to explore how gender influences risk perception in pregnant women with GD and their male partners, (2) to determine the role these women see their partner as having in aiding efforts at health behavior change, and (3) to understand information and support needs. **Design/Methods:** Couples ( $n = 16$ , 8 couples) recruited for the quantitative component of the study participated in individual semi-structured interviews. Interviews were transcribed verbatim and analyzed using qualitative description. Content analysis was used to code and analyze the data. **Findings:** Risk perception was shaped by factors such as simultaneously acknowledging GD risk while minimizing personal risk. Participants expressed confidence in their ability to manage GD and felt they had an adequate amount of GD knowledge. Participants, and especially male partners, held several misconceptions regarding GD. Couples agreed factors such as emotional support, making changes together, of partner attendance at prenatal care visits, prompt follow-up, and personalized dietary plans were important in reducing risk perceptions. **Conclusions:** This study contributes to the understanding of pregnancy risk perception by examining the role of gender. For nurses, awareness of the influence of the woman's partner and his role in contributing to health behaviour change are key to understanding the social context of a pregnancy complicated by GD.

### **Unpacking Service Delivery Practices in Navigation: Learning From Service Providers About the Facilitating and Hindering Elements Informing Navigational Support to Individuals With Neurodevelopmental Disabilities and Their Families**

Sandy Litman, *Glenrose Rehabilitation Hospital*

Rosslynn Zulla, *University of Alberta*

David B. Nicholas, *University of Calgary*

The service delivery landscape serving children with neurodevelopmental disabilities (NDD) and their families encompasses multiple sectors including health, education, and social care. Complementing data from families, data from individual and group interviews were qualitatively analyzed, based on 31 service providers in Alberta. Findings demonstrate a range of approaches related to service delivery. Specifically, participants offered a range of philosophical and operational "underpinnings" that reflected differences and affected experience and practice as follows: (i) orientation to

children with NDD and their families (e.g., proactive vs. reactive; strength/asset vs. deficit-oriented; focus on the brain/medical model vs. holistic/social model) and (ii) empowering/engaging versus disempowering/marginalizing (e.g., encouraging the voice of the child and/or family, varied prioritization/valuing of some service providers/resources/sectors over others) and active versus passive practices (e.g., frequent vs. ad hoc vs. almost nonexistent capacity-building initiatives such as workshops to broaden knowledge and nurture empowerment). To facilitate the navigation experience for individuals with NDD, their families, and service providers, participants emphasized the need to create an integrated service approach that is premised on proactive principles and relationship-building across sectors, including ongoing professional and family development opportunities as well as attention to how service providers related across sectors/services and reach out to families. Building structurally based models of navigation and information-sharing need to include interactional and relational strength amongst professionals/para-professionals and between families and these service providers appears urgently needed. Implications of these findings will be discussed in relation to building navigational support that promotes collaborative service provision for families affected by NDD.

### **Women's Motivation to Consent and Adhere in a Clinical Trial for Fear of Cancer Recurrence Group Intervention Research**

Valerie Lok, *McGill University*

Tse Mali, *McMaster University*

Galica Jacqueline, *Queen's University*

Maheu Christine, *McGill University*

Between 22% and 99% of cancer survivors will experience some level of fear of cancer recurrence (FCR), and more than half of survivors will experience moderate-to-high FCR. Maheu et al. developed and tested a 6-week cognitive existential (CE) group intervention clinical trial (CT) to assist women diagnosed with breast and ovarian cancers to cope with FCR. The objective of this study is to explore women's motivation to consent and adhere to a CE group intervention CT for the management of FCR. A secondary objective is to explore women's experiences in taking part in such a group intervention. This study employs an interpretive descriptive design with semi-structured interviews. The themes and patterns from the narrative content of 10 women were analyzed through a qualitative content analysis as well as a constant comparative analysis. The women's accounts featured four overarching themes: (1) individual motivators and (2) societal motivators were relevant to women's motivation to consent, while (3) structural influences and (4) emotional support were important components to adhering to the weekly group sessions. Understanding cancer survivors' reasons for consenting and adhering to a CT intervention are important to increase successful recruitment into and implementation of CTs. An important implication for

practice is the influence of emotional and social support received from the women in the group sessions, which had a major impact on their adherence to the CT. Clinical group leaders and facilitators should capitalize on creating group cohesion to promote emotional and social support to lead to better group adherence.

### **Exploring the Natural Development of Health Literacy in Thailand Incorporating More Culturally Sensitive Methodological Approaches**

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Ungsinun Intarakamhang, *Behavioral Science Research Institute, Srinakharinwirot University*

Most research on health is based on Western models. Here, we focus on the challenges involved when attempting to undertake health research in more culturally sensitive ways. The study examined how health literacy (HL) develops naturally in families as this is a neglected area, despite HL being a crucial factor in improving public health. Most HL interventions are delivered to patients. Thailand has low HL and has seen significant increases in noncommunicable diseases linked to poor health care practices. This study explored how HL develops naturally. A purposive sample of healthy parents with healthy children who lived in either rural or urban areas with low HL participated in extended semi-structured interviews. The interview contents were designed to go beyond Western models of HL and included material that Thai health psychologists judged to potentially be culturally based influences on health beliefs and behavior. The data were analyzed using thematic analysis. Data saturation was achieved after interviewing 12 parents. While 10 themes emerged, of particular interest was the ways in which the Thai collectivist culture influenced several themes. Individuals perceived their health education responsibilities as extending beyond their immediate family to the wider community. Religion and religious practices particularly Buddhism influenced motivation, attitudes, and behavior in beneficial ways with meditation, mindfulness, and the concepts of Karma, loving kindness, and acceptance all being mentioned. Working across cultures raised challenges which will be discussed, but we conclude that an understanding of the influences of culture is crucial in designing effective HL education.

### **Community-Based Rehabilitation in Outdoor Settings: A Systematic Review of Qualitative Articles on People With Disabilities and Professionals' Experiences and Perceptions**

Louise Sofia Madsen, *Department of Public Health, Aarhus University*

Charlotte Handberg, *The National Rehabilitation Centre for Neuromuscular Diseases*

Claus Vinther Nielsen, *DEFACTUM, Central Denmark Region*

This systematic review sheds light on the link between community-based rehabilitation (CBR) approaches and outdoor settings. The aim was to examine and synthesise qualitative knowledge on people with disabilities' and professionals' experiences and perceptions regarding facilitators and barriers to CBR approaches in outdoor settings. Six electronic databases were searched (PubMed, Embase, Scopus, PsycINFO, CINAHL, and Cochrane Library) for qualitative articles. The qualitative research methodology Interpretive Description was applied to synthesise and analyse the extracted data material. In total, 4,029 abstracts were identified; nine articles met the inclusion criteria. CBR in outdoor settings appears to strengthen the ability of people with disabilities to overcome challenges through engagement in outdoor adaptive activities and inclusive social communities. This is transferred into a culture of reciprocal interaction which emerge among, for instance, people with disabilities, professionals, volunteers, and family members. However, the differences in the outdoor setting seems to complicate the professional role and challenge delivery of outdoor CBR. For practice implications, the findings indicate that CBR in outdoor settings may be considered a beneficial alternative to rehabilitation in institutional settings. For people with disabilities to empower their ability to overcome challenges, outdoor CBR provides opportunities to deal with everyday life issues. In addition, outdoor CBR contains potential to address social barriers, confront stigmatization about disability, and increase participation opportunities.

### **The Understanding and Management of Stroke Risk in Patients With Atrial Fibrillation in Northern British Columbia**

Ali Marleau, *University of Northern British Columbia*

Davina Banner-Lukaris, *University of Northern British Columbia*

Lela Zimmer, *University of Northern British Columbia*

Kenneth Prkachin, *University of Northern British Columbia*

Atrial fibrillation (AF) is the most common cardiac arrhythmia in the world. AF affects 1% of the global population and 8% of Canadians over the age of 65 years. AF was once considered a benign condition but is now seen as a significant public health issue as a result of the profound impact upon mortality and morbidity. AF is a common predicting factor for ischemic stroke and can cause a 500% increase in stroke risk. This study aimed to fill a gap in the current literature by investigating a demographic that has not been studied and explored how



healthcare providers can improve uptake of preventative measures against stroke. This study investigates the understanding and management of stroke risk in patients with AF living in northern British Columbia through the use of in-depth interviews, using a qualitative–descriptive design. Data were analyzed thematically using NVIVO 11 into three separate themes: living with AF, stroke prevention, and navigation. Overall, participants lacked sufficient knowledge about their stroke risk and the significance that oral anticoagulation plays in decreasing their risk for stroke. Results from this research suggest that more work needs to be done in educating people by raising awareness about the link between AF and stroke risk and highlight the importance of people diagnosed with AF taking oral anticoagulation.

### **Little Saskatchewan First Nation Youth's Experiences of Forced Displacement and Resettlement Using Participatory Videos**

Donna Martin, *University of Manitoba*

Shirley Thompson, *Natural Resources Institute, University of Manitoba*

Sochimaobe Nweze, *College of Nursing, University of Manitoba*

In this presentation, we describe participatory video research methods in detail. We initially discuss how participatory video research methods were applied to engage Little Saskatchewan First Nation community members (youth, Elders, council members) in a depiction of the lived experiences of a human-made flood in 2011, forced displacement, and eventual resettlement in 2018. Youth and an elder engaged in all film-making processes, except for hands-on editing, with the films providing compelling evidence of the community members' suffering stemming from the 2011 human-made flood. Films included visual and audio accounts of the flood's impacts on the ecosystem, family systems, and community. Each successive film documented another few years of displacement and culminated in the provision of a video-production workshop with Little Saskatchewan First Nation youth. Seven years of forced displacement created an enhanced awareness about the injustice of targeting First Nation communities with diverted flood waters and provoked social change. In 2019, our research team facilitated a workshop with the youth to provide them with the skills to film issues associated with resettling. We compared the uptake of the films versus citations from our publications. Based on our assessment of the process and outcomes, we argue that participatory video is a noteworthy approach in qualitative research as it facilitates participation, collaboration, and knowledge translation. By using participatory video, Little Saskatchewan First Nation community members and the researchers informed the general public and government officials about the urgent need to collaborate with First Nations to determine a joint plan for water/land management.

### **Factors and Strategies Influencing the Uptake of Male Circumcision as an HIV-Preventive Measure in High HIV and Low Male Circumcision Prevalence Settings**

Thandisizwe Mavundla, *University of South Africa*

Pule Solomon Moabi, *Scotts College*

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) remain the leading global burden of disease, especially in Southern Africa. As such, efforts to develop innovative preventive and curative measures continue to be a global priority. Of late, the World Health Organization recognised and recommended mass male circumcision (MC) as an adjunct HIV-preventive measure in 14 selected sub-Saharan African countries. However, despite efforts to promote the uptake of MC in these countries, the uptake remains significantly below set targets. The purpose of this article is to describe factors and strategies influencing the uptake of MC as an HIV-preventive measure in high HIV and low MC settings. The study was designed for all settings of high HIV and low MC prevalence; in particular, our data were collected from Botswana, Lesotho, South Africa, and Zimbabwe. A qualitative, explorative, descriptive, and contextual study was conducted using in-depth unstructured individual interviews with 50 uncircumcised men who are aged between 29 and 83 years from samples collected from the abovementioned four countries. Tesch's method of descriptive data analysis was followed. Data analysis revealed a number of themes, namely (1) perceived health beliefs (protection from diseases, sexual beliefs, and personal hygiene), (2) perceived community-held beliefs (stigma, traditional, and religious obligation), (3) men's knowledge regarding circumcision, and (4) perceived misconceptions about circumcision (the right time for circumcision, myths, and contraindications to circumcision). A model was developed with the central concept "promote the uptake of MC."

### **Dealing With Troubled Conscience in Care of Older People With Dementia**

Monir Mazaheri, *Department of Health Sciences, The Swedish Red Cross University College*

Eva Ericson-Lidman, *Department of Nursing, Umeå University*

Öhlén Joakim, *Institute of Health and Care Sciences, Sahlgrenska Academy, Centre for Person-Centred Care, University of Gothenburg*

Astrid Norberg, *Ersta Sköndal Bräcke University College; Department of Nursing, Umeå University*

A feature of healthcare system, particularly in the care of older people, is its cultural diversity in terms of having considerable numbers of both caregivers and care recipients with an

immigrant background. Considering the influence of culture in ethical decision-making processes, the idea of conscience, and the adverse effects of a troubled conscience, it is important to study these issues in culturally diverse populations. There are no published studies regarding troubled conscience among immigrant populations that include enrolled nurses. The aim of the study was to illuminate the meanings of troubled conscience and how to deal with it among enrolled nurses with Iranian backgrounds working in Swedish residential care settings. The study conducted with a phenomenological hermeneutical design. Ten nurses were interviewed. Analysis included noting a naive understanding of text as a whole followed by a structural analysis. Five subthemes and two themes were identified. The meanings of having a troubled conscience include not being a good person, being an uncaring person, not acting according to one's values, and living in a state of unease. Dealing with a troubled conscience involves trying to compensate for the harm one has caused and trying to prevent similar situations in the future. The nurses understood themselves as caring people and not only caregivers. They knew that they should hear their conscience and respond to it by trying to be a caring person and acting according to their values.

### **Researcher as Interlocutor: A Phenomenological Methodological Technique**

**Corey McAuliffe, University of Toronto**

This presentation reflects on the methodological challenges arising from participation as both researcher and participant within my phenomenological dissertation research. My study explored the tacit and existential structures that underpin U.S. and Canadian women graduate students' experience of global public health practice while applying Max van Manen's reflective inquiry of five existential guides (relationality, corporeality, spatiality, temporality, and materiality). It was my original intent to use anonymous stories from my three in-depth phenomenological interviews alongside all other interview participants. Through the analytical use of van Manen's existential guides, I identified differences and challenges within my interviews compared to those of the other participants. For example, temporally, the timing of my interviews proved problematic, insofar as I was interviewed before, during, and after creation of all participant data. Thus, my interviews began to include responses and insights connected to other participants' experiences. Materially, I had access to literature, all data created, and my own stories throughout the research process, while my participants could only interact with their data through our interviews and email correspondences. While I realized my data might be problematic for my intended use, they proved to engender a powerful analytic tool, allowing for deep reflexivity throughout the research process. This led to a conceptual evolution of researcher as participant to researcher as interlocutor. An explanation of both the challenges and potential strengths of employing researcher's experiences within a

participant context are discussed along with using interviews of the researcher as a reflexive analytic technique to increase study rigor and trustworthiness.

### **Supporting Mainstream Schools to Implement Inclusive Education**

**Carol McKinstry, La Trobe University**

**Teresa Iacono, La Trobe University**

**Amanda Kenny, La Trobe University**

Education is a human right for all including students with disability. Internationally, inclusive education has been promoted widely and supported by legislation in some countries. Models and strategies such as Universal Design for Learning have been adopted or recommended in both mainstream and special education schools. The aim of the study was to explore options that could enable specialist schools to support and assist mainstream schools to implement more inclusive education strategies. As part of a large project using multiple method research design, a qualitative study was conducted. Semi-structured interviews were conducted with a range of stakeholders ( $n = 32$ ) associated with Victorian schools in Australia. These included parents, principals, allied health professionals, teachers, and education support staff. Support from mainstream schools is being provided by some mainstream schools; however, it varies in schools. Examples of support include peer support for teachers, written information or resources, provision of professional development sessions for teachers, and some classroom peer support and team teaching. There is untapped potential for specialist schools to provide more support to mainstream schools through building closer and more formal relationships. Inclusive education can be enhanced at the individual teacher level or using a whole school approach. Use of allied health professionals such as occupational therapists and speech pathologists would also enhance inclusive education. Allied health professionals such as occupational therapists and speech pathologists have a vital role to play to improve educational and occupational performance outcomes of student with disabilities in both specialist and mainstream schools.

### **A Systematic Review: Health Literacy Interventions to Improve Health Outcomes in Low/Middle-Income Countries**

**Salima Meherali, University of Alberta**

**Neelam Saleem Punjani, University of Alberta**

**Amynah Mevawala, University of Alberta**

Health care systems in many low- and middle-income countries (LMICs) face considerable challenges in providing high-quality, affordable, and universally accessible care. In an effort to find feasible solutions to these issues, a lot of

importance is given to HL interventions for people living in LMICs. Limited studies have examined the impact of different interventions and communication strategies for improving HL of people living in LMICs. To respond to this paucity of information, we sought to synthesize the literature to provide a comprehensive understanding of effectiveness of HL interventions on improving the health information needs of people living in LMICs. Search strategy was developed and implemented to identify relevant evidence. Data from 23 published research studies were systematically analyzed. Study findings were divided into four themes including traditional HL interventions, art-based HL interventions, interactive learning strategies, and technology-based HL interventions. The studies suggest that traditional and art-based HL interventions are more effective in improving the health outcomes of people. Studies have also highlighted that multiple HL strategies and interventions are also useful in improving the HL of the population. All the HL interventions were effective and have significantly improved the knowledge and awareness level of the population. However, based on the literature review, we found significant evidence of limited HL interventions being delivered through innovative and technological learning strategies. In addition, the sustainability and scalability of these interventions are not clear. Therefore, future research concerning sustainability measures for effective health literacy interventions in LMICs is still needed.

### **Using Event History Calendar as a Quantitative and Qualitative Tool in Exploring the Social and Emotional Problems Among Adolescents**

Faniswa H. Mfidi, *University of South Africa*

Adolescence is a period of substantial change which carries a lot of social and emotional problems. Studies have shown that adolescents suffer a lot of emotional turmoil which manifests itself as either internalising problems such as depression, anxiety, and shyness or externalising problems such as aggression, anger, and defiance. As such, many studies endorse a need for an effective universal mental health promotion intervention programmes as the key to dealing with the emotional and social problems that are associated with adolescence. Purpose: This article purports to assess the applicability and effectiveness of using an event history calendar (EHC) as both a quantitative and a qualitative tool in exploring the social and emotional needs of adolescents. The study was based on the core principles of the synergistic approach proposed by Hall and Howard. **Method:** A mixed method design using the EHC was conducted. The EHC developed by Martyn and Belli to assess adolescent sexual risk behaviours was adopted and adapted. The adapted EHC was used to explore the frequencies, patterns, and trends in social and emotional problems of school going-adolescents and approaches they used to deal with these problems. The 5-year grid EHC comprising some relevant domains based on the five competencies in the

CASEL (2013) social and learning model was developed following pilot conversations with 12 school-going adolescents on the main topic of study. Random systematic sampling was used to recruit 347 school-going adolescents aged 15 to 19 years from four schools in both urban and rural settings to complete the EHC and from which further qualitative subsample for the semi-structured interviews was selected. Sequence analysis of the data from the EHC and thematic analysis of semi-structured interview transcripts were done concurrently. **Results:** The study was able to generate descriptive analytical data from the adapted EHC and semi-structured interviews. This study ascertained that an event history calendar could be effectively used as a quantitative and qualitative tool. **Conclusion:** The synergistic consideration of the qualitative and quantitative findings showed consistency in the factors that propagated the social and emotional problems which were experienced by the adolescents. This is a clear demonstration that quantitative and qualitative methods are not in opposition to one another but rather supplement each other to give richer findings. The study further enhances the utility and effectiveness of the EHC in not only answering the why but also the how of the phenomena under study.

### **Spiritual Health as a Protective Health Asset for Mental Health in Canadian Adolescents**

Valerie Michaelson, *Brock University*

**Background:** The word spirituality and its cognates are used in a wide range of public documents related to health, including international health promotion reports, Canadian high school health curricula, and the Convention on the Rights of the Child. Despite all of this, spirituality is rarely considered routinely in the health of child populations in Canada. The overall goal of our study was to use scientific evidence to explore spiritual health as a protective health asset to the mental health of Canadian adolescents. We built our inquiry on an established conceptual framework that considers spiritual health to be the strength of one's connections in four relational domains (to oneself, to others, to nature, and to some kind of transcendent; however, one understands that domain). **Methods:** Strand 1 of our mixed methods design involved a qualitative study, which was guided by an interpretive description methodology. Our sample included 74 young Canadians (ages 10–18 years), and data were collected through focus groups and semi-structured interviews. Strand 2 involved an epidemiological analysis of a national survey of 23,920 young Canadians (ages 11–15, years 2013–2014). Findings from both strands were combined iteratively through an emergent approach to integration. **Results:** Spiritual health related strongly and consistently to many indicators of positive mental health and appeared to operate as a protective health asset for mental health. The domain "connection to self" appeared to be driving the observed protective effects. The youth-informed definition that emerged from our data provides a framework for operationalizing

spiritual health in a wide range of health-related contexts. When interpreted in light of each other, findings from both strands of this study suggest that a broadly conceived framework of spiritual health may be of great practical value for supporting the mental health of Canadian adolescents. **Discussion:** By intentionally illuminating the ideas and experiences of real Canadian adolescents and providing insight into large, generalizable patterns, these data open up a fresh way of looking at the relationship between spirituality and mental health. It forces us to revisit assumptions we may hold about the contribution that the spiritual dimensions of health can potentially make to the lives of Canadian young people.

### **Are Primary Healthcare Providers in British Columbia Able to Recommend and Provide Pertussis Vaccine in Every Pregnancy?**

Hana Mijovic, *BC Children's Hospital*

Devon Greyson, *University of Massachusetts*

Julie A Bettinger, *Vaccine Evaluation Center, BC Children's Hospital Research Institute*

Vaccination against pertussis during pregnancy has the potential to substantially reduce disease among infants. In 2018, the Canadian National Advisory Committee on Immunization officially recommended pertussis vaccine for every pregnancy. However, given low uptake of the already-recommended prenatal influenza vaccine, achieving optimal pertussis vaccination levels is expected to be a challenge. Healthcare provider's recommendation is a key influencer of maternal vaccine acceptance. In order to optimize pertussis vaccine uptake in pregnancy, it is important to understand what factors influence providers' ability to consistently recommend and provide pertussis vaccine. As the first stage of a multi-method qualitative study exploring providers' vaccine confidence, we conducted semi-structured, individual phone interviews with 12 British Columbia (BC) perinatal providers (6 family physicians, 4 midwives, 2 nurses), representing diverse practice settings. We interpreted these data using qualitative thematic analysis, informed by Interpretive Description. BC's perinatal providers' ability to recommend and provide pertussis vaccine was strongly influenced by health system-level factors. *Role designation* of individual perinatal providers in pertussis vaccine recommendation and provision was not established, resulting in missed opportunities for vaccine counseling. Providers' ability to make a strong recommendation in support of vaccine was hindered by inconsistent *vaccine availability*. Finally, providers felt that lack of public funding further contributed to inequitable *vaccine access* for marginalized women. BC perinatal providers and the women they serve would benefit from an inclusive, province-wide pertussis vaccination strategy. Early experiences from BC are pertinent to the implementation of vaccination programs in other provinces.

### **What's Foucault Got to Do With It? Using Foucauldian Discourse Analysis to Examine Family Involvement in Mental Health Legal Processes**

Darren Mills, *Otago Polytechnic; Auckland University of Technology*

Deborah Payne, *Auckland University of Technology*

Kirk Reed, *Auckland University of Technology*

Approximately 10,000 New Zealanders per year experience compulsory assessment and treatment for a mental disorder. However, the Aotearoa New Zealand's Mental Health (Compulsory Assessment and Treatment) Act, 1992, which shapes this process was recently identified as outdated. The 2018 national inquiry into mental health and addiction services has called for new legislation that reflects modern approaches to human rights and which align with international commitments, specifically the principles of the Convention on the Rights of Persons with Disabilities. The inquiry noted that the views of family/whānau (extended family) need to be better incorporated into consultation processes. Currently, Section 7A of the Act directs the responsible clinician to consult with family to notify the proposed treatment pathway arising from compulsory assessment. Although Section 7A aims to strengthen family involvement and address their concerns regarding legal processes, the guidelines on their rights are vague, leading to potentially exclusionary practices. Consultation between the responsible clinician and family at this point in the process is pivotal as discussions may impact the outcome of the assessment process and need for involuntary hospital admission. This presentation emphasises how a Foucauldian discourse analysis can offer insight into the role of consultation within compulsory assessment and treatment processes. Tools that aid a Foucauldian discourse analysis are offered to depict how problematizing the consultation process enables examination of subject positions and power relations. Identifying how prevalent discourses might subjugate family/whānau or offer other power positions can open up new possibilities that can challenge current practices situated within the existing legal framework.

### **Integrating Input From Service Providers and Service Recipients Relative to Developmental Disability and Mental Health Issues: Toward Knowledge for Action**

Wendy Mitchell, *University of Calgary*

Rosslynn Zulla, *University of Alberta*

David B. Nicholas, *University of Calgary*

A population-based study found that 4.5% of Canadian children have a disability; of these, 73.5% meet criteria for neurodevelopmental disabilities (NDD). Cerebral palsy, autism spectrum disorder, and fetal alcohol spectrum disorder are

specific NDD. Parents raising children with NDD require an array of services across sectors such as health, social services, and education. Unfortunately, the system of care is often fragmented, suboptimal, and difficult to navigate. Particularly concerning are the 30–50% of individuals who present with NDD and a coexisting mental health problem (dual diagnosis). These individuals and their families face additional challenges accessing appropriate and unified care, often encountering multiple barriers within and between systems of care. As part of a larger study, interviews and focus groups were conducted with 85 service providers and service recipients in relation to navigational services for children with a dual diagnosis in urban, rural, and remote communities in Alberta. Service providers and families indicated that there was a lack of coordinated services, especially in rural areas, that crisis was often the service catalyst, and that parents play a key role, although parental care, preparation for the long haul, and training are sorely lacking. Peer support for families was highly valued and recommended as it addresses parent isolation, is nonjudgemental, and offers hope to families. There is also a need to make information more accessible for families and service providers. Mentorship programs are being piloted in Edmonton and Calgary, with learnings informing how to disseminate the programs provincially. Implications and recommendations will be offered.

**“This Model Has Really Turned Her Life Around”: Social Capital and Quality-of-Life Outcomes Among Persons With Intellectual and Developmental Disabilities Involved in Microboards**

Rae Morris, *School of Social Work/Canadian Institute for Inclusion and Citizenship, University of British Columbia*

Tim Stainton, *School of Social Work/Canadian Institute for Inclusion and Citizenship, University of British Columbia*

Celeste Borja, *School of Social Work/Canadian Institute for Inclusion and Citizenship, University of British Columbia*

Persons with intellectual and developmental disabilities (IDD) face multiple barriers to community inclusion that can have detrimental impacts on health and quality of life. A community-based initiative in British Columbia has attempted to address this gap through the generation of Microboard structures. Microboards are designed to promote community inclusion in an innovative way by steering away from the traditional block funding model towards a network-based individualized funding approach. While anecdotal feedback on Microboards has appeared to be promising for social capital and quality-of-life outcomes for this population, there is limited formal research to date examining this assumption. The current presentation

highlights the results of a university–community partnership and qualitative exploration of the experiences of persons with IDD and their Microboard members in relation to social capital and quality-of-life outcomes. Semi-structured interviews were conducted with 21 participants involved in Microboards across the province of British Columbia. Interviews were audio-recorded and transcribed for analysis of thematic content by the research team. Emerging themes were shared with Microboard members for member checking and credibility. Findings suggest that Microboards as autonomous, empowering, and person-centered resource networks contribute to the enhancement of social capital and quality of life among persons with IDD. The current presentation will provide an overview of thematic findings as well as considerations and recommendations for future research and healthcare practices in this area. The results of this qualitative study can help to guide research and policy aimed at improving health outcomes for persons with IDD.

**Conflict Transformation in Community-Based Participatory Research With the Montagnard Tribal Refugee Community: Implications for Qualitative Health Research**

Sharon Morrison, *University of North Carolina Greensboro*

Xuem Xiu, *University of North Carolina Greensboro*

Andrew Young, *Community Advisory Council, Montagnard Dega Association*

Community-based participatory research (CBPR) is a framework for health disparities research with underserved and diverse minority communities. CBPR is guided by nine key principles of engagement, with emphasis on relationship building, trust, shared decision making, ethical reciprocity, empowerment, and social change. It is particularly useful for bringing attention to social conflicts and tensions that impact ethnically diverse refugee and immigrant community participation and leadership in qualitative health research. In this presentation, we use a series of vignettes (i.e., stories and scenarios generated from community work) to illustrate how CBPR partnership initiatives with the Montagnards, an indigenous group from the highlands of Vietnam, illuminated and transformed the dynamics of social conflicts in this tribal refugee community. We provide an overview of the initiatives and discuss historical and current features of conflicts encountered and negotiated during our work. We apply a conflict transformation lens to our discussion and reflect on how this approach can inform future CBPR and qualitative health research endeavors.

**Navigating End-of-Life Care Discussions After the Legalization of Medical Assistance in Dying (MAiD)**

Christopher Ng, *University of British Columbia*

**Soodabeh Joolaei, Center for Health Evaluation and Outcome Sciences (CHÉOS); Nursing care Research Center, Iran University of Medical Sciences**

**Anita Ho, Centre for Applied Ethics, University of British Columbia; UCSF Bioethics; Centre for Health Evaluation and Outcome Sciences (CHÉOS); BMC Medical Ethics**

The recent legalization of Medical Assistance in Dying (MAiD) in Canada has proven to be difficult for healthcare providers navigating end-of-life (EOL) care. Even as palliative/hospice healthcare providers (PHCPs) are experts in EOL care, they now face an added layer of challenge in managing the delicate balance between discussing MAiD and traditional EOL care options. Our study explored the experiences of PHCPs in caring for patients before and after the legalization of MAiD in 2016. This presentation will discuss findings from our qualitative content analysis of semi-structured interviews with 26 interprofessional PHCPs in Greater Vancouver (Canada), focusing on the challenges faced by PHCPs when discussing MAiD in the context of providing holistic EOL care. Participants faced difficulties interpreting whether abstract patient conversations regarding their wishes to die were inquiries for MAiD or requests for more information on broader EOL care options. Navigating the best ways to promote patient autonomy and well-being, PHCPs reported the need to further explore patients' EOL concerns before having MAiD conversations. There were notable differences among participants regarding how much PHCPs should explore traditional palliative/hospice care options with their patients before MAiD discussions and whether PHCPs should probe patients on their desire to receive MAiD. Our rich data yielded valuable insights on PHCPs' perspectives on navigating traditional EOL care conversations compared to MAiD discussions and provide suggestions on how PHCPs can better handle these intricate conversations to best support patients' EOL care decisions.

### **Service Access and Navigation Needs of Children With Neurodevelopmental Disabilities in Rural Communities in Alberta**

**David B. Nicholas, University of Calgary**

**Rosslyn Zulla, University of Alberta**

**Sandra Litman, Glenrose Rehabilitation Hospital**

Children with neurodevelopmental disabilities require services across sectors including health, education, and mental health. As part of a larger project exploring service navigation needs, group interviews were conducted with 15 parents and 18 service providers in rural communities in Alberta, based on a participation action research approach. Data were analyzed using Interpretive Description. Participants identified a lack of awareness about access to and availability of services as well as quantity/quality of services. They described sometimes

not knowing what to ask of service providers/systems. Concerns were raised about key transitions such as youth to adulthood, given markedly fewer service options as youth aged. Wait times and limited availability of services were compounded by extended travel distances. Services were described as ill-equipped to address the breadth of child needs, and restrictive eligibility criteria reportedly limited access. Parents identified rural schools as community "hubs" for connecting with services; however, schools were seen as insufficiently equipped to meet the breadth of child/youth needs. Coordination of care was identified as a major gap, warranting navigators and centralized services. Care access was limited by a lack of information sharing across services. Staff vacancy and turnover were a key concern, with extensive delays in filling vacant positions. Conversely, a sense of community/solidarity was noted in some rural locales whereby parents reportedly supported one another, exchanged ideas, and sought to organize supportive collectives. Rural service providers noted strength in local partnerships and the importance of relationships with stakeholders, including engagement with families. Implications and recommendations will be provided.

### **Intersectional Stigma and Perinatal Substance Use Services: Recognizing the Power of the Good Mother Ideal**

**Tracy Nichols, University of North Carolina Greensboro**

**Amber Welborn, University of North Carolina Greensboro**

**Meredith Gringle, University of North Carolina Greensboro**

People with addiction disorders who receive medication-assisted treatment (MAT) face stigmatization for both their addiction and their treatment method. Many people, even healthcare providers, view MAT as replacing one drug with another, and long-term use of these prescribed substances is often viewed as a moral failing. For pregnant women on MAT, the stigma and shame increase exponentially. This study examines the intersectional stigma attached to perinatal substance use generally and maternal opioid use specifically. Using data from a 6-year grounded theory study on perinatal substance use service provision, the article describes the ways that service providers both perceive and enact stigmas of addiction and harm reduction when good mothering ideals are violated. Study sources included observational and interview data from providers across healthcare and social services as well as publically available documents that detailed responses to perinatal substance use. Situational analyses, conducted to develop the grounded theory model, identified intersectional stigma as a critical contextual construct. Additional analyses, conducted for the findings reported here, included a reimmersion into a subset of the data to identify and deconstruct stigma processes. Examples of social stigma, in the form of interactional

discrimination, and of self-stigma are presented to argue for the importance of making visible the role of good mothering ideals in stigma associated with maternal opioid use. Functions and processes of intersectional stigma within the context of service provision are examined to illuminate the complexities of the effect of stigma on patient–provider interactions and the implementation of best practices.

### **Providing Services to Pregnant Women Affected by Substance Use: A Grounded Theory Study**

Tracy Nichols, *University of North Carolina Greensboro*

Meredith Gringle, *University of North Carolina Greensboro*

Amy Lee, *University of North Carolina Greensboro*

Due to the complex nature of women's drug use, comorbid conditions, and their role in childbearing and rearing, pregnant women affected by substance use require multiple social and healthcare services. Gender-responsive and trauma-informed care, coordinated across agencies and systems, is considered critical to achieving positive outcomes for mother and baby. However, limited resources and stigmatizing beliefs are barriers to effective care provision. Few studies address the process and experience of providing services to a stigmatized population within and across systems. This study sought to develop a process model of service provision for pregnant women affected by substance use grounded in the perspectives and experiences of providers. Data collection lasted 6 years and consisted of interviews, focus groups, observations, and document review. The study was bounded within the state of NC, USA, where dramatic increases in maternal opioid use were fueling renewed interest in the issue. Analyses followed constructivist grounded theory principles and included Clarke's situational analysis techniques. The resulting model portrays structural-, interpersonal-, and individual-level processes that occur across complex adaptive systems and affect providers' ability to provide both services and care. Central to the model is the threat of custody loss that permeates structural- and interpersonal-level processes and mediates care provision through experiences of strong emotions. The model accounts for the role of emotions in integrating compassionate care and service provision. Understanding perinatal substance use services from both a systems and service provider perspective can assist in developing and refining systems of coordinated and compassionate care.

### **Developing Insights Through Dialogic Partnership: A Way of Being a Sensitive and Analytic Qualitative Researcher**

Roli Pandey, *Indian Institute of Technology, Kanpur*

A dialogic partnership necessitates that in a research dialogue, while co-constructing meanings of experiences, neither the

researcher nor the participant has power over the other. It requires some form of sharing on researchers' part too; where in the process both the researcher and the participant get coloured with one another's experiences. In an 18-month-long ethnographic study, that aimed at understanding, suffering, and healing experiences of parents with an ASD child, the significance of such sharing was understood by the researcher. The study was conducted in a small city of India with over 30 sets of parents. The facilitative process of sharing which helped in building a "dialogic partnership" highlights that the process of sharing involves sharing of knowledge, sharing of emotions, and even sharing of silences. It signifies that the quality of being a qualitative researcher lies in handling the gaps between the participants and the researcher by being sensitive in their approach. This sensitivity helped the researcher in being more analytic towards the participants' experiences, which gradually shaped the findings of the study. The findings were obtained by utilising the constructivist grounded theory approach, where constant role of being sensitive and developing insights highlights the intense process of analyzing the data.

### **"Searching the World of ASD" in Tier II cities of India: Journey of Suffering and Healing, in the Context of Healthcare System**

Roli Pandey, *Indian Institute of Technology, Kanpur*

Autism spectrum disorder (ASD) is considered to be one of the most demanding childhood developmental disabilities that a family can face, primarily because of the tribulations or distress its characteristics (i.e., limitations in social communication and interaction, and restricted and repetitive behaviour) can bring about in its members. The notion of growing as a normal family gets disrupted with the advent of ASD. In a country like India, what often becomes distressing for the parents with ASD child is not only the stigma surrounding ASD but also the drastic changes in their roles, relationships, and the perceived future in the financial, familial, physical health-related, social, and systemic domains of their lives. In this article, I will discuss the Indian parents' experiences regarding self-growth (healing) along with those of intense distress (suffering) from an interdisciplinary approach of new cross-cultural psychiatry. In-depth semi-structured interviews were conducted with 30 sets of parents for over 18 months. Their subjective experiences of suffering and healing were understood through the emergent categories obtained by utilising constructivist grounded theory approach. It was found that the major source of distress of being a parent to an ASD child was related to the parents' distressing experiences within health care system. Category 1—feelings of "chaos and confusion" regarding ASD features, category 2—"victim of resentment within the healthcare system," and category 3—"distress of aimless wandering" explained the demoralisation they received by the healthcare system. Despite this, they consistently "re-moralized" themselves by "forming their own world of ASD," as explained in category 4. The findings of this study highlight the significance

of “transference of care” among various stakeholders and some implications for health care providers who work with the marginalized parents with ASD child.

### **Families Victim of Violence Committed by a Relative With Severe Mental Disorders: A Grounded Theory**

Etienne Paradis-Gagné, *Department of Nursing, Université du Québec à Trois-Rivières*

Dave Holmes, Sue & Bill Gross School of Nursing, *University of California*

Violence against family members perpetrated by a relative with severe mental disorders is common in forensic psychiatry. Studies show that more than half of families living with a mentally ill person experience violence on a regular basis; the social, psychological, and physical impacts of this violence are significant. To examine this issue, which remains relatively unexplored in research, a qualitative study with family members who have experienced this type of family violence was conducted in a forensic psychiatric hospital. Semi-structured interviews were conducted with 14 family members. Grounded theory was used as the methodological approach, and the work of French poststructuralist author Jacques Donzelot served as the theoretical framework. Donzelot theorizes the family as a privileged instrument for the government of populations. Qualitative analysis of the data led to the identification of five different themes: (1) medicolegal apparatus, (2) experience of violence, (3) family’s responsibility toward the violent relative, (4) exclusion and stigmatization, and (5) suffering and resilience.

### **Rigorous and Collaborative Data Analysis**

Cathie Scott, *PolicyWise Children & Families*

Naomi Parker, *PolicyWise Children & Families*

Jo-Louise Huq, *PolicyWise Children & Families*

Recognizing and reducing bias and addressing questions of trustworthiness, rigour, and relevance in qualitative research are critical if research findings are to be applied in practice. This is especially true and challenging in relation to the analysis of qualitative data in multi-researcher and evaluator teams. We’ve created a framework to guide collaborative analysis of qualitative data by adapting Michael Quinn Patton’s approach to analysis of qualitative data. This framework has been applied consistently across many projects, with five different project managers and # research and evaluation associates. The framework focuses on a collaborative approach to coding, identifying patterns, themes, and interpretation. Woven throughout the framework is engagement (contextualization) with end users and participants. We’ve emphasized both practice-informed evidence and evidence-informed practice. The result has been

high-quality, contextual findings through a rigorous and collaborative approach.

### **Revealing Expert Thinking in Nursing Using an Action Method**

Cynthia Peden-McAlpine, *School of Nursing, University of Minnesota*

Joan Liaschenko, *University of Minnesota*

Mary Fran Tracy, *University of Minnesota*

Kathie Krichbaum, *University of Minnesota*

The purpose of this study was to interpret the actions displayed by expert nurses’ in their narratives to reveal their thinking when solving complex problems of practice. Schön’s reflection in action is the framework supporting the study method. Nurse managers were asked to nominate 40 expert nurses based on criteria of expertise. These expert nurses were asked to participate in a 2-hr narrative interview asking them to reflect on their actions in situations where they solved complex problems from their practice. The interviews were audio-taped and transcribed for analysis. The strategy designed for data analysis is an original interpretive approach focused on the actions the nurses demonstrated in their narratives. Narrative captures the temporal order of actions and events in an organized scheme or plotline. The plotline displays meaningful actions that convey the experience (i.e., the experience of expert thinking). The philosophical premise behind the interpretive strategy is that human action is intentional and goal-directed and can be interpreted to better understand the thought behind the action. The plotline representing the sequence of action was reconstructed in each narrative to reveal the thought processes of the nurses. Each narrative was interpreted with the following questions in mind. What features does the nurse notice when recognizing the problem, what are the criteria by which the nurse made the judgment, how is the nurse framing the problem, and what types of information did the nurse use? An example of a narrative will be used to illustrate the interpretive analysis strategy.

### **Scoping Review of the Association Between Mental and Sexual Health in Adolescents: Evidence From Lower/Middle-Income Countries**

Neelam Punjani, *University of Alberta*

During puberty and sexual debut, adolescents experience drastic physical, mental, and social transformations. To deal with these changes, adolescents may become vulnerable to mental health problems. The aim was to synthesize published research evidence on sexuality-related mental health stressors among adolescent girls and boys, identify gaps (if any) in current evidence, and contribute to the state-of-the-art knowledge about the experiences of stressors related to sexual health



among adolescents to further inform research, practice, and policy initiatives in sexual health. A scoping literature review of peer-reviewed articles published between 1990 and 2018. MEDLINE, CINAHL, Embase, PsycINFO, Global health, ERIC, and Sociological Abstracts databases were searched for research studies that focused on the experiences of sexual health-related mental health stressors and symptomatology of adolescents. We targeted studies conducted with adolescent populations with ages 11–24 years. Data from 12 published research papers, including 8 qualitative studies, 3 quantitative studies, and 1 mixed method study, were systematically analyzed. Six themes were identified regarding sexual health and mental health of adolescents: a meaningful connection of sexuality and mental health, myths, and misconceptions related to sexuality; lack of adequate knowledge, awareness, and services on sexuality; poor parental and teachers support; social and cultural influences; and educational needs among adolescents related to sexuality. Unmet needs for accessible, adolescent-friendly sexual health services, counseling, and age-appropriate information contribute to several mental health stressors and symptoms such as sadness, depressive and anxiety symptomatology, regret, fear, embarrassment, low self-esteem, guilt, shame, and anger. Therefore, tackling sexuality-related stressors could play an important role in addressing the overall well-being of young people.

### **Using Arts-Based and Somatic Approaches to Future Form a Healthy Sexual Culture With Bisexual Emerging Adult Men and Transmasculine Individuals**

Katherine Querna, *University of Minnesota*

**Introduction:** Bisexual cis-men/trans-masculine emerging adults (B/TMEA), the focus of this research, must negotiate multiple systems of sexuality/gender-based discrimination. The scant research that exists suggest that they tend to have higher rates of mental, physical, and sexual health decrements compared to monosexual peers. Yet, this story is incomplete; B/TMEA also show personal and group resilience by implicitly and explicitly challenging norms of sexuality, gender, identity, and conceptions of “community.” These important disruptions can not only benefit B/TMEA as individuals but can also strengthen queer communities, allies, and others with social justice commitments by challenging them move towards an ethics of activism that is more reflexive, inclusive, and kind, resulting in healthier, more resilient communities. **Methods:** This research uses narrative/arts-based/somatic methodologies to cocreate knowledge with 15 participants. **Results:** Two primary themes were constructed: (a) cishetero/cishomonormativity: reproduction, resistance, and dissonance (including gendered socialization through relationships across the social ecology) and (b) finding myself: who I was, who I am, and who I am becoming. This second theme will be the focus of my contribution to this panel. **Conclusion:** This research complicates the oft-taken exclusively social constructionist approach

to identity categories, highlighting the importance of socialization (including shifting masculinity norms) and biology. Expanding conceptions of sexuality, gender, and identity can help bolster individual and community resilience.

### **Perspectives of Ward-Based Primary Health Care Outreach Teams on mhealth Initiatives in Community-Based Care in Northern Cape: A Template Analysis**

Mokholelana Ramukumba, *University of South Africa*

Various forms of mHealth applications, for example, AITA, Mobenzi, and eWBOT have been introduced in South Africa to support health data management at households and community levels. A number of studies have been conducted on mHealth in South Africa. The focus has been on the structure and function of the community health workers programme in relation to mHealth applications. To date, there is paucity of research studies on the perspectives of the users of mHealth applications.

This study aimed to explore the perspectives of ward-based primary healthcare outreach teams on the influence of mHealth applications on their roles and responsibilities in primary healthcare Northern province. This study utilized a qualitative methodology and employed a template analysis as a specific research design and a tool of analysis. Data were collected from three focus groups using a semi-structured interview schedule. The principles of template analysis were adopted for data analysis. Three main themes emerged. Maximum support, effective health data management, and lastly, technical challenges. There were seven subthemes. The teams were happy and satisfied with the technology, and the application enabled them to provide efficient care and increase access of the community to healthcare.

The study concluded that mHealth is a useful initiative in community-based care. Ward-based primary health care outreach teams’ main functions were well supported by this application. The technical challenges highlighted require new policy directives to sustain the programme.

### **Carrots, Rivers, and Backyards: Metaphorical Expressions From a Focused Ethnography of Suicide Intervention Gatekeeper Training Implementation**

Patti Ranahan, *Applied Human Sciences, Concordia University*

Jennifer White, *School of Child and Youth Care, University of Victoria*

Between 2015 and 2018, the Canadian Mental Health Association—British Columbia Division—received funding from the provincial Ministry of Health to implement standardized suicide prevention gatekeeper training. This presentation

summarizes findings from a focused ethnography documenting the implementation process as it unfolded, with particular focus on the metaphors used by participants to describe the complexities of implementation. Data included 24 individual interviews, 50 hr of field observations, and a number of relevant documents. Analysis suggested that the initial focus on program implementation shifted towards marketization of the training (i.e., constructing responsibility to help, drawing upon authoritative knowledge) and creating the conditions for community readiness (i.e., healing and community development, place, and context). “Carrots,” “rivers,” and “backyards” were metaphorical expressions deployed by participants to describe the process of implementation as it unfolded. Metaphor analysis brings to life the research findings by offering insights into the complexities of implementation work within diverse contexts, including social and cultural understandings, actions, and sense-making of participants involved in the initiative.

### **#HearMeToo: Application of a Time line Method in Sexual Assault Research**

Susan Rees, *School of Psychiatry, University of New South Wales*

Lisa Simpson, *Community Health Sexual Assault Service, Sydney Local Health District*

Sexual abuse is a strong predictor of future psychiatric problems. We undertook a mixed methods study to provide a more nuanced qualitative understanding of the mental health outcomes, in the context of interpersonal responses from family members toward survivors after sexual abuse, to help to better inform prevention and interventions. The paper from the study is currently in press. In this presentation, we will describe the mixed method approach which included the Mini-International Neuropsychiatric Interview (MINI, 5.5.0) and the novel application of a qualitative time-line method to map and identify with each participant the contextual factors and mediating emotional responses associated with mental disorder following sexual abuse. The time-line method involves a large sheet of paper, where the researcher and participant work together to plot on a visual time line the events and emotional reactions of interest to the study, adding extensive notes regarding each element of the sequence. The method enabled in-depth recording of interpersonal interactions and the survivor’s emotional responses and their associations with mental disorder symptoms across the life course. A key focus was on the description of events that hindered or helped recovery after the sexual abuse and those which may have increased risk for mental disorder or multiple sexual assaults across the life span. Specific disclosure experiences that were recorded occurred spontaneously with no prompting by the counselor. The method enabled researchers to draw tentative temporal connections between the events (sexual abuse), the response of the interpersonal world, and the survivor’s psychological state,

allowing for an exploration of how each factor might have influenced or impacted on the others.

Within the mixed methods approach, the qualitative interview was the predominant data source because it provided the descriptive associations of women’s personal and interpersonal experiences as they influenced mental health outcomes following sexual assault. Participants were 30 adult survivors of sexual abuse, seeking support from the Sexual Assault Counselling Service, Sydney Local Health District, Australia. We will discuss the findings and consider why the method was particularly useful from a clinical and research perspective and why the participants valued the experience of using a time line with the research assistant.

### **Engaging With First Nations Women With Experiences of Breast Cancer Using Digital Storytelling**

Kendra Rieger, *University of Manitoba*

Marlyn Bennett, *Faculty of Social Work, University of Manitoba*

Donna E. Martin, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Tom F. Hack, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

In Manitoba, breast cancer mortality has increased for First Nations women while it has decreased for all other women. As well, First Nations women are significantly more likely to be diagnosed with advanced breast cancer. Western approaches to Indigenous research and healthcare practices have had limited effectiveness on patient outcomes. When research is conducted from a Western paradigm alone, the findings and resultant policies ignore health practices of Indigenous peoples and fail to align with their healthcare priorities. There is a need to employ Indigenous research approaches to identify reasons behind these escalating rates and to integrate Indigenous knowledge into current healthcare services. Guided by two-eyed seeing and a framework for patient engagement, we engaged with First Nations women to assess the feasibility and meaningfulness of using digital storytelling to explore their breast cancer experiences. We held a two-day digital storytelling workshop, which incorporated ceremony, talking circles, and a feast. Our conversations with the women were profound and provided deep insights into First Nations women’s experiences with breast cancer. They told stories which illuminated the strengths that they drew upon to find healing and also the challenges they experienced within the healthcare system. Based on their feedback on the digital storytelling workshop, we are embarking on a new research project in which the workshop participants have become full research team members. This collaboration has ensured that our future research plans are not only relevant, acceptable, and feasible but also culturally safe and guided by direct input from these women.

## **Promoting Engagement and Collaboration: Communities of Practice in a Healthcare Context**

Patricia Samson, *Faculty of Social Work, University of Calgary*

David Nicholas, *Faculty of Social Work, University of Calgary*

Debra Samek, *Provincial Social Work Practice Lead, Alberta Health Services*

A collaborative community–university partnership resulted in a qualitative study that utilized a focus group methodology to: (1) examine how social workers practicing within health care services in central and northern areas of a Western Canadian province understand communities of practice (CoP); (2) help define, contextualize, and revisit existing theories and definitions of CoP modalities as they apply to, are understood by, and practiced in both health and human service fields; and (3) design a model of a CoP that can support ongoing professional development for social workers in this context. A CoP can become a mechanism for lifelong learning that fosters critical thinking and reflective practice and highlights learning as a process of mutual engagement, collaboration, and participation in support of linking research to practice. Emerging research findings point to an interest in measuring the effectiveness of CoP in healthcare settings. In this study, a sample of 24 social workers participated in five focus groups, in person and virtually. Findings from a thematic analysis of the data address some gaps in social workers' knowledge within this setting via social workers sharing their existing understandings around the CoP phenomenon; elucidating a deep and rich understanding of CoP within social work services specifically as they relate to this practice context; revealing some key ingredients contributing to a unifying definition of CoP within urban vs. rural healthcare contexts; and gaining an understanding of the lived experience of CoP.

## **Patient and Family Experiences, Relational Safety, and the Need for Enhanced Ethical Oversight of Quality Improvement Initiatives in Health Care: A Qualitative Study**

Brenda Sawatzky-Girling, *University of British Columbia*

Patricia Rodney, *University of British Columbia*

Sam Sheps, *University of British Columbia*

Michael McDonald, *University of British Columbia*

Improving the quality of care and reducing avoidable harm to patients/families are important obligations for health care professionals and institutions. However, quality improvement (QI) involving patients at the point of care raises ethical questions about unexamined wider impacts on patients. This qualitative

doctoral research challenged the assumption that QI involving patients is necessarily a beneficial and benign extension of routine medical care. I explored patient/family experiences of pilot QI interventions that gave patients a new opportunity to improve the quality of their own care.

Relational inquiry and ecological systems theory framed this ethical (value-based) analysis of agents in context. Using interpretive description methodology, I explored two case studies (hand hygiene interventions) on two hospital units. Over a 12-month period (~140 hr), I observed patient care and staff meetings, interviewed patients/families/staff (patients  $n = 25$ , families  $n = 8$ , care providers/volunteers  $n = 21$ , other staff  $n = 17$ ), and analyzed documents.

Findings about patient/family experiences of the QI interventions showed that a multifaceted set of reactions, perceptions, and behaviours occurred at once. My thematic analyses centred on the value patients/families place on positive connections with providers and health care settings. My conceptualization of relational safety in health care explains how relational connections result from interactions with others and are linked to relational safety (feeling safe and valued) and trust. I recommend strengthening relational safety by conceptualizing and operationalizing QI as an ethical endeavour and adopting a relational, multilevel perspective to ethical oversight of QI. I close with reflections on methodological and ethical aspects of my study.

## **Exploring Formative Diversity and Inclusion Life Experiences: Lessons Learned From Semi-Structured Life Course Interviews of Faculty at a Medical School in the Eastern United States (USMS)**

Elissa Schuler Adair, *Harvard Medical School*

Emorcia V. Hill, *Harvard Medical School*

Joan Y. Reede, *Harvard Medical School*

In the United States, academic and public debate continues about diversity and inclusion, affirmative action, and their benefits. Diverse disciplines including education; law; social science; business; ethnic, gender, and sexuality studies; and the health professions have identified potential benefits related to prejudice reduction, communication, enhanced information processing, content knowledge, analytical skills, innovation, social agency, self-concept, self-awareness, civic/community engagement, and leadership. However, meta-analyses have not unequivocally demonstrated that the types of diversity and inclusion programming health professionals receive yield benefits that ultimately improve clinical outcomes or the quality of patient experience. To begin to concretely understand the potential benefits derived and how these likely connect to specific medical education competencies and professional development, an exploratory/pilot qualitative study was conducted May–July 2019 with current faculty who also graduated from

the USMS between 2000 and 2015. Twelve faculty participated in a 60-min semi-structured interview that included a retrospective lifeline visualization to elicit descriptions and sequences of formative Diversity & Inclusion based on USMS faculty's own D&I definitions. This framing guided discussion yet allowed faculty to think aloud and revise and then reflect on how their own life course uniquely evolved. Faculty identified 10 positive and negative D&I categories they considered formative. Preliminary insights suggest that high-contrast exposures and small-group discussions matter. This pilot highlighted some methodological approaches for measuring and cautiously interpreting highly individualized data from a small sample as further studies or interventions are planned.

## Methods for Client Feedback

Cathie Scott, *PolicyWise for Children & Families*

Kelsey Duebel, *PolicyWise for Children & Families*

Naomi Parker, *PolicyWise for Children & Families*

Piloting innovative and responsive data collection methods to collect feedback from diverse and often vulnerable child and youth presents complex challenges and opportunities for learning. In this presentation, we will discuss the methods piloted, challenges encountered, and lessons learned through the Child Intervention Client Feedback Project in the context of the Alberta's Child Intervention system. The aim of the project was to identify recommendations for future system-wide client feedback data collection tools that empower and honour the voices of clients while building knowledge about clients' experiences to lead to system improvement. Data collection methods were designed to be inclusive, strengths-based, culturally responsive, and trauma-informed. Quantitative data were collected through an online survey while qualitative methods were adapted from traditional methods for age-appropriate and culturally relevant contexts. Arts and play-based methods were used to collect feedback from children ages 4–9, sharing circles were conducted to collect feedback from Indigenous children and youth ages 10–23, and face-to-face interviews were conducted for children and youth ages 10–23. Collaborative mixed methods data analysis revealed robust findings. Qualitative methods provide context, nuance, and depth needed to fully understand the trends illustrated by quantitative methods.

## Exploring Barriers to Lifestyle Advice Provision to Pregnant Women With Obesity

Michaela Senek, *University of Sheffield*

Madelynne Arden, *Sheffield Hallam University*

Hora Soltani, *Sheffield Hallam University*

**Background:** Over half of maternal mortality is associated with being overweight during pregnancy. This study explored healthcare professionals' (HPs) barriers to providing weight

management advice to pregnant women with obesity who were part of an mHealth feasibility randomised controlled trial (RCT) lifestyle intervention. **Aim:** To conduct a process evaluation of a feasibility RCT and to explore barriers to lifestyle advice provision to pregnant women with raised body mass index (BMI). **Methods:** Semi-structured interviews were conducted with eight HPs who were purposefully sampled. The interviews lasted between 30 and 60 min. Braun and Clark's thematic analysis allowed for recording of patterns across the data. The approach sought to elaborate and clarify quantitative findings from the feasibility RCT. A descriptive approach fitted in with the overall purpose of conducting a mixed methods sequential explanatory design. Theme development was purely inductive. The researcher was free to code the data and find patterns of themes. A second researcher reviewed the codes and emerging patterns. **Findings:** Two main themes emerged: professional limitations due to lack of time and training and personal factors such as stigma linked to HPs own BMI status. **Conclusion:** Despite the steep rise in the number of women of childbearing age who enter the pregnancy in an obese state, no additional programs have been put in place to better equip HPs for this challenge. Due to limited resources and feeling of time pressures, implementation of additional steps in the care pathway is perceived as a challenge.

## Readiness and Feeding: The Transition From Hospital to Home With a Late-Preterm Infant

Jessica Shillington, *University of Calgary*

Deb McNeil, *Alberta Health Services*

Shelley Raffin, *University of Calgary*

Parents of late-preterm infants have identified inadequate preparation to manage their newborn's unique needs at home, yet little is known about their hospital discharge experience. This study aims to describe the perspectives of parents surrounding their transition from hospital to home with their late preterm infant (born between 34 weeks and 36 weeks and 6 days gestation). Twelve parent participants, nine mothers, and three fathers were recruited from Calgary, Alberta, and shared their experience through in-person interviews and one focus group. Interpretative description was used to guide the study, and data were analyzed through interpretive conceptual analysis and description. Key themes were revealed to be "feeling ready" and "fed is best." These two themes support parents' transition home with their late preterm infant and are influenced by "previous parenting experience" and the "discharge care setting." Parents described verbal approval from healthcare professionals, early community follow-up, and discharge teaching specific to their late preterm infant's unique characteristics to increase their feelings of readiness to transition home. Feeding was parents' most significant challenge, and they expressed a "fed is best" stance indicating that breast milk is nutritionally superior and yet feel the most important thing for their newborn is to feed and grow.

Mothers and fathers should be supported to take care of themselves and choose a feeding method works best for them and their family. In hopes of reducing feeding challenges, parents need to be educated on the behavioral characteristics of their late preterm infant before leaving hospital and have teaching reinforced in the community.

### **A Qualitative Evaluation of Postnatal Experiences and Perceptions of a Technology-Based Peer Support Intervention Program for Asian Mothers at Risk of Postnatal Depression**

Shefaly Shorey, *National University of Singapore*

Social support is known to reduce risks of postnatal depression and improve maternal emotional well-being. While many preventive efforts have experimented with technology, professionals, and paraprofessionals in providing social support to mothers in need, most studies determined the effectiveness of their interventions through quantitative measurements of maternal outcomes. Therefore, this study aimed to evaluate the postnatal experiences of Asian mothers at risk of postnatal depression and the perceptions of peer volunteers regarding a technology-based peer support intervention program (PIP). A qualitative semi-structured interview was conducted with 20 Asian mothers at risk of depression (10 from the control group and 10 from the intervention group) and 19 peer volunteers from a randomized controlled trial. The PIP includes weekly correspondence between peer volunteers and mothers through any telecommunication means over 4 weeks. All interviews were approximately 30–60 min long, audiotaped, transcribed verbatim, and analyzed using thematic analysis. Two overarching themes (“postnatal experience” and “evaluation of the PIP”) comprised a total of five themes and 14 subthemes emerged. Mothers from both the control and interventions groups were generally satisfied with hospital care and the support received from family. However, mothers who received the PIP tend to have more positive outlooks of their birth experiences. Overall, peer volunteers and mothers involved in the PIP found the PIP useful and expressed satisfaction with the program’s flexibility. The positive endorsement of the PIP by peer volunteers and mothers suggests the success of the PIP in maintaining positive maternal emotional well-being during the postpartum period. With the help of technology, hospitals can easily provide additional peer support to at-risk mothers in addition to existing standard care offered to these mothers.

### **Dimensions of Behavioral Health Access Across the Continuum: How Qualitative Data Was Used to Inform Massachusetts’ Policy**

Jenna T. Sirkin, *Norc at University of Chicago*

Anna Robinson, *Abt Associates*

Claire Hoffman, *University of North Carolina*

Alicia Sparks, *Abt Associates*

We assessed barriers and facilitators for individuals interacting with law enforcement to access behavioral health services in Middlesex County, Massachusetts. Adapting Penchansky and Thomas’s model of access to health care treatment, we characterized access dimensions—availability, accessibility, affordability, accommodation of individual needs, acceptability of care, and individual/family experience—as moderating diversion from arrest or emergency departments and the process of making timely connections to behavioral health services. Using a purposive sampling approach, we conducted 10 interviews with stakeholders who are responding to behavioral health crises and a focus group of individuals and family members with lived experience from January–April 2019. We analyzed data using thematic analysis. Our findings revealed that law enforcement implemented diverse strategies to support identification and response to behavioral health needs/crises such as investing in specialized training, adopting co-responder models, establishing relationships with local providers, and initiating community outreach efforts. While local efforts have increased arrest diversion, stakeholders identified regulatory, transportation, resource, and data sharing barriers to diverting individuals from emergency departments. Focus group participants emphasized the importance of agency across the care continuum, challenges finding a provider who was the “right fit,” and lack of continuity of care. Stakeholders also noted a lack of viable alternatives for crisis intervention and timely behavioral health care in the community, especially for individuals with complex medical needs, the elderly, children, and individuals who exhibit aggressive or violent behavior. Policy makers are exploring viable alternatives to arrest or emergency departments for individuals in need of crisis intervention or behavioral health services.

### **Qualitative Evaluation of a Pilot Adverse Drug Event Reporting Platform to Inform Future Design and Change Management Activities**

Serena Small, *University of British Columbia*

Ellen Balka, *Simon Fraser University*

Corinne M. Hohl, *University of British Columbia*

Adverse drug events (ADEs) are harmful and unintended consequences of medication use and are a leading cause of emergency department visits and hospital admissions in Canada. Poor informational continuity of care among clinicians in a patient’s circle of care contributes to the recurrence of ADEs. ActionADE is research- and user-driven software that enables the documentation of patient-specific ADE information. We developed ActionADE as a paper-based prototype in conjunction with clinician end users using participatory design

methods and subsequently built ActionADE as a stand-alone, web-based application. We piloted ActionADE among pharmacists at one hospital in June 2018 using a mixed methods approach. Using a focused ethnographic approach for the qualitative component, we assessed the usability, clinical utility, and effect on workflow of ActionADE. For the quantitative component, we collected utilization statistics to evaluate use and report completion rates. Report completion rates and software usability were high. We identified human factors that influenced user experience, including workflow interruptions, diagnostic uncertainty, and patient handover. Users highlighted areas to enhance their user experience, which we will use to refine the software. We will also use the findings to develop robust change management and user education strategies to maximize uptake among end-users and minimize the impact of risks identified in the qualitative evaluation. In the next research phase, we will integrate ActionADE with PharmaNet (BC's Drug Information System) in a pilot project with the support of the Ministry of Health and evaluate its effect on reducing recurrent ADEs through a randomized controlled trial.

### **Advocating for Relational Research Methodologies in Mental Health Care Research**

Krista Socholotiuk, *Simon Fraser University*

Mihaela Launeanu, *Trinity Western University*

In mental health research, reliance on audio data where individuals constitute the unit of analysis reflects the underlying philosophical assumptions of dominant Western methodologies. While some areas of inquiry lend themselves well to this approach, an individualistic focus at the level of methodology may be at odds with health research that emphasizes the relational and contextual aspects of human life. Even when health researchers view human beings as relational beings, the majority of research methods available to us continue to restrict the types of questions that can be asked and the participants who can be involved.

From a methodological standpoint, this is a problematic case of incongruence, and the result is a perpetuation of an individualistic focus that is very restrictive, particularly in terms of examining relevant human experiences and actions, such as those that occur in communities, families, or practitioner–client dyads. Researchers who recognize the need to conceptualize the entire study from a relational perspective will discover that the quality of relational methodologies in the literature is highly variable. Some of these approaches are relational in name only as they continue to approach human experiences as individual experiences disconnected from relationships and social context, while others are attempting to be more innovative. This article will: (a) offer a systematic review and critique of existing relational methodologies, (b) make the case that a truly relational methodology must be responsive to the

phenomena of study, and not vice versa, and (c) provide methodological suggestions for developing and implementing relational research practices.

### **Challenging Student Nurses' Perspectives of What Constitutes Patient Centred Reflective Practice Using Innovative Technology**

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Reflective practice is an essential exercise to teach nursing students so they can improve, enhance, or change their practice to provide patient-centred care. A dilemma exists with this practice because nurses are not taught to reflect from the patient's perspective, but they are only taught to self-reflect or peer reflect. This causes a divide between the theoretical purpose of reflective practice and the pedagogical approaches used to teach students. A single case study, modeled after Merriam, was designed to provide students with the opportunity to reflect from the patient's point of view. A simulation scenario was created where the patient who was nonverbal and ventilated was equipped with a GoPro® camera on his forehead. The students were required to provide care and then watch the video from the patient's perspective. Twenty-one students participated in semi-structured debriefing interviews, written reflections, and reviewing their care from the patient's perspective. This experienced challenged students' perceptions of their care causing them to consider the implications of the patient's environment, the proximity of care they deliver, their communication styles, and unearth the concept of "doing for." Most significantly, the reflections were focused on the patient point of view instead of how the student experienced the interaction with the patient. This innovative strategy used to teach reflective practice to students has the ability to transform reflective practice and make it truly patient focused.

### **The Struggle Between Ancient Welfare Thinking and Prevailing Health Care Policy in Scandinavian Health Care Legislative Documents**

Ellinor Tengelin, *University West*

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Åse Boman, *Department of health sciences, University West*

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Traditional welfare state systems in Scandinavia are challenged by new governance systems. Demands for efficiency and productivity in healthcare increase, raising questions about patients' positions and agency. This also implies ethical dilemmas for healthcare professionals. Comprehensively, analysing the findings of previous discourse studies on how the patient is constructed in central policy texts, this study compares the position of the patient and the accompanying ideological struggles in Norway, Sweden, and Denmark. The purpose was to compare and discuss the findings of discursive constructions of patients in law and policy text from the three countries. We found an ideological struggle across the Scandinavian countries, operating at a political level, a legislative level, and a healthcare level, with variation in how the new value-based patient care is constructed. We conclude that national governance systems still exert hegemonic power by strongly influencing patients' degree of choice and autonomy. The Scandinavian countries may all be heading towards a commercial healthcare market, despite their tradition of a welfare model of healthcare. Today, healthcare strategies move in the opposite direction, controlled by politicians' financial goals. The ideological struggle between welfare state governance and other governance systems may exist also in other Western countries in our globalized world.

### **Using a Qualitative Descriptive Approach to Understand Decision-Making Practices in Priority Setting and Resource Allocation Within Health Care Systems: An International Comparative Perspective**

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Craig Mitton, *School of Population and Public Health, University of British Columbia*

Spending in health care has grown considerably over the last decades in all developed countries. Aging populations and novel technologies are usually deemed as the main drivers for such unsustainable trend in the finances of health systems. In this scenario, setting priorities for investments becomes a central concern. Making hard choices in a rational, evidence-informed, systematic, transparent, legitimate, and fair manner has constituted an increasingly important target. Notwithstanding the voluminous body of literature in this area, most of the work focus on developing and improving prescriptive approaches as well as presenting case studies. Our ultimate aim was to describe existing practices of priority setting and resource allocation within the context of publicly funded health care systems of high-income countries. An online qualitative survey was used with decision makers and academics from 18

countries. Four hundred and fifty individuals were invited, and 58 answered the survey questionnaire. This work presents key methodological aspects of this research and also its theoretical underpinnings. Dialoguing with Sandelowski's seminal paper on qualitative descriptive studies, we contend that a researcher engaged in this endeavor acts like a composite sketch artist collecting pieces of information from "policy-making witnesses" in order to draw a valid depiction of reality. Moreover, we discuss relevant insights pertaining sampling, data collection, and data analysis in the realm of international comparative studies. Our work indicates that online qualitative surveys can be successfully used to expand the international analysis of public policies to topics hitherto little appraised from a comparative perspective.

### **Dimensional Analysis: Growing a Program of Scholarship With Method and Theory**

Clare Whitney, *University of Pennsylvania School of Nursing*

Jane Evered, *University of Pennsylvania School of Nursing*

Conceptually driven programs of health research illuminate complex human phenomena in ways that can improve practice. In the current climate of health science academic training, many emerging scholars undertake secondary analyses or take part in large existing studies for their culminate projects. This trend is due in part to increasingly shortened doctoral time lines and the allure that joining a lab or center holds for early-career scholars. We argue that refining objects of scholarly study in a relationally based field such as nursing often requires a different approach. We aim to show that Leonard Schatzman's interpretive interactionist grounded theory method, dimensional analysis, is a philosophically and theoretically sound method for establishing and growing programs of inquiry. Using examples from our application and teaching of dimensional analysis method, we demonstrate why the method is advantageous and pragmatic at each stage of nursing doctoral study. Specifically, we will demonstrate how dimensional analysis method grounded our own work from data-driven concept analysis, through PhD dissertation, to postgraduate inquiry. Dimensional analysis is distinct from other methods used to generate grounded theory, as it explores the nature of phenomena, focusing on all of their dimensions. Ultimately, dimensional analysis also primes scholars for other interactionist grounded theory methods including situational analysis and constructivist grounded theory. Additionally, situation-specific theories propel further study using quantitative, qualitative, or mixed methods, with implications for practice. A necessary counterpoint to positivist evidence, dimensional analysis method, positions scholars substantively and methodologically to develop and flourish in independent careers that transcend their academic training.

## **Firefighters' and Fire Officers' Experiences of Co-Responding With Ambulance Services to Cardiac Arrest Calls in the UK**

Julia Williams, *University of Hertfordshire Professor*

Carl Smith, *East of England Ambulance Service*

Fire and rescue authorities across the UK took part in a co-responder trial, working alongside ambulance services to provide a medical response to patients in cardiac arrest. This study explores the experiences of firefighters and fire officers to generate a new understanding of the impact on fire crews of responding to cardiac arrests and the implications for future training and support both at a local and national level. Using an interpretative phenomenological approach, including a variety of methods such as focus groups, interviews, and triads, in-depth accounts of the participants' experiences of co-responding emerged.

Twenty-nine participants took part via two focus groups, five triads, two one-to-one interviews with firefighters, and three one-to-one interviews with fire officers. Thematic analysis, guided by a framework of clinical reasoning, generated four themes: (1) social setting, (2) training, (3) performance review, and (4) staff well-being. Findings revealed a difference in experiences between on-call and whole-time firefighters, with all participants seeking specific training to communicate with relatives and a desire to learn how to be more effective in these situations.

In rural areas, co-responders play an essential role in supporting ambulance services. Role expansion needs to be weighed against the cost to mental health and well-being of fire and rescue staff involved. Targeted training is vital to support co-responders supporting ambulance services, and this article will discuss areas for consideration if co-responding is to be adopted on a large-scale basis to provide timely responses to life-threatening health emergencies in a failing healthcare service.

## **A New Perspective on Continuing Mental Health Education: A Case Study on How Reflective Practice Can Improve Resilience in Paramedics**

David Wolff, *St. Francis Xavier University*

Paramedics witness life, and death unfold almost daily. As a stress resiliency strategy, the question the adult education literature leaves is whether or not an individual (paramedic) can learn how to prepare for their potential critical stressors. The objective of this case study is to identify whether paramedics can become transformational learners, self-initiating their own cognitive restructuring and seeking out opportunities to change; to become critical thinkers to adapt to; and to accommodate new meanings derived from experiences into their belief structures, as a resiliency strategy. To answer this question, the study looks to see whether and how paramedics use

reflective practice to learn in order to navigate the daily, potentially traumatic, experiences they are presented with.

Using a lens of transformational learning, the data reveal that the learning that comes from a new paramedic's early experiences can have lifelong effects on the individual's resiliency. All participants of this study indicated use of a reflective practice and that the ability to process and reflect on their daily critical stressors was partially learned through their early guided experiences by supportive mentors and built on prior life experiences. Each described a change in themselves; a new norm, as a result of experiencing paramedic critical stressors and emphasizing the importance of a foundation of life experience, and early career guided critical reflection to teach paramedics to become critical thinkers to adapt to and to accommodate new meanings derived from experiences into their belief structures as a resiliency strategy.

## **"It's Very Stressful But I love It": Advanced Nurse Practitioners' views of Advanced Nursing Practice**

Emily Wood, *University of Sheffield*

Rachel King, *University of Sheffield*

Steve Robertson, *University of Sheffield*

Tony Ryan, *University of Sheffield*

In the UK, the role of advanced nursing practitioner (ANP) has several definitions but is not regulated separately from nursing in general. As such, there has been concern that ANP means different things in different places. In 2018, we began recruiting to a prospective cohort study, which currently has 143 participants, who were invited to complete a core questionnaire. The cohort will provide longitudinal data on a broad range of important questions, including those relating to work place well-being, but also gives an opportunity to conduct "bolt on" qualitative studies. One such qualitative study has been completed, with the aim of providing explanatory insight into the findings of the quantitative phase. A subsection of cohort members was purposefully selected, and approached for interview, with a focus on work place well-being. Twenty ANPs agreed to be interviewed. Interviews were semi-structured and conducted over the telephone at a time and date convenient to the participant. Interviews were audio recorded, transcribed, and analysed using Braun and Clark's six-step process. Thematic analysis allowed for the systematic exploration of the data set around a focused range of topics while simultaneously providing scope for interpretation. At each stage, analysis was conducted separately by two members of the team, who came together to agree codes and finalise themes. Findings provide insight into the challenges and sources of satisfaction for ANPs and provide further methodological understanding for the use of cohort studies as a means for recruitment to qualitative research.



## **Understanding Social Prescribing for People With Comorbid Mental and Physical Health Conditions. A Realist Evaluation**

Emily Wood, *University of Sheffield*

Sally Ohlsen, *University of Sheffield*

Scott Weich, *University of Sheffield*

Sarah Jane Fenton, *University of Birmingham*

The UK government has committed to a widespread expansion of social prescribing. Social prescribing is a way of connecting patients with community resources to help improve health and well-being and reduce isolation. It is important to understand how and why social interventions have the potential to affect change. A realist evaluation was used to explore how social prescribing is accessed and used by adults with coexisting physical and mental health conditions and what is working (or not) and why.

The realist evaluation was conducted in a social prescribing organisation serving a socioeconomically deprived area in the North of England. Using an iterative process of 30 interviews and follow-up workshops with key stakeholders, the mechanisms (M) and context (C) behind outcomes (O) were explored in complex CMO statements, refined and developed into a programme theory.

The programme theory was mapped onto the salutogenesis theory of health. Stakeholders reported outcomes as increased health knowledge and more appropriate service use (comprehension); increased ability to self-manage and reduced stress (manageability); and increased social connectedness, confidence, and self-worth (motivation). Clients were empowered to mobilise and reflect on the resources they already have available to them (enabling their “sense of coherence”).

Social prescribing enables people to cope with stressors and move in a health promoting direction by using a person-centred asset (strengths)-based approach to increasing comprehension, motivation, manageability. By applying theory to social prescribing, we have attempted to develop a theoretical explanation for its popularity and the positive findings from case studies.

## **“It was Hard”: A Pilot Study of Military Spouses of Veterans With Post-Traumatic Stress Disorder**

Teresa W. Yambo, *National Military Family Association*

This pilot study was conducted to identify common themes to describe the experience of military spouses living with veterans with PTSD and refine the interview guide and design methods in preparation for a full phenomenological dissertation study. A face-to-face interview was conducted from a purposive sample using Husserlian phenomenology. Participants described what it is like to live with a veteran with post-traumatic stress disorder. Data were analyzed using the Colaizzi phenomenological analysis method.

Among the military spouses, three themes emerged: his story is her story, it was hard, and he was a different person. Findings indicate that military spouses’ day-to-day living became interwoven with the veterans’ symptoms of PTSD. Methodological design concerns noted in the pilot study were incorporated into the larger study.

## **Alone Together: Exploring Rural Connectivity Through Multimedia, Participant Action**

Olive Yonge, *University of Alberta*

Deirdre Jackman, *University of Alberta*

Jill Konkin, *University of Alberta*

Clinical placements in rural health care sites have been shown to foster community and interprofessional values for students in the allied health sciences. This is particularly beneficial in breaking down long-standing disciplinary silos and hierarchies in health care, as students carry these values forward into practice. Over 3 years since 2016, the researchers have carried out an innovative, participant action initiative, employing the hybridization of online photovoice and digital storytelling methods. Three successive cohorts of students, undergoing rural, clinical co-placements in Nursing and Medicine, have taken part. With each iteration, the participatory research cycle of data collection, analysis, and output provides a more nuanced understanding of rural, interprofessional culture and a safe, democratic forum for students to exchange ideas and build interprofessional identities. The latest project data support a view of rural health care as a dialectic of independence and interdependence. Like all rural community members, clinical practicum students learn to be autonomous and resourceful but also connected across professional, social, and spiritual dimensions. Participants’ photographs and words moreover show that this connectivity is mediated by place. Relationships are built around specific sites such as nursing desk and the report room, the fitness centre and the coffee shop, the public park and the backwoods trails. Seen in this context, rural interprofessionalism is part of a larger system of social capital and holistic connectedness within the community into which students are drawn during their rural placements. Through their images and stories, they become powerful advocates for the rural experience.

## **How Do We Navigate Service Delivery Systems? A Scoping Review of the Literature on the Evidence of Navigation Relative to Neurodevelopmental Disabilities and Health Issues**

Rosslynn Zulla, *University of Alberta*

David B. Nicholas, *University of Calgary*

Lucyna Lach, *McGill University*

Building a navigation program for individuals with neurodevelopmental disabilities (NDD) and their families requires a comprehensive understanding of how families with children with NDD search for services. To address this goal, a scoping review identified studies that examine how parents with NDD search and/or find different service providers who work across different sectors. After entering relevant search terms into the database, 2,744 citations were retrieved and 30 citations met the screening criteria. Of the 30 papers, there were 17 qualitative articles, 7 quantitative articles, and 6 mixed methods articles. Findings from the review demonstrate the following trends about the experience of “accessing services” or “finding services”: (i) the phenomena are difficult to define given the large focus of the literature on listing challenges, facilitators, or steps to access services; (ii) experiences are largely located within a North American context with limited understanding of how different social identity groups experience this phenomenon; and (iii) experiences are often discussed without reference to the influence of structural and discursive factors (e.g., policies, organizational practices, and political climates) that shape how parents interact with service systems. Findings suggest that experiences of finding or accessing services comprise “functional” and “relational” activities that largely are viewed at a microlevel (between parents and providers) or at a meso-level (between different providers) but not at structural levels. Implications of this narrow view will be discussed as it relates to how “navigation” should more accurately be viewed as a “systems” construct and thus look at individual–organizational–structural interactions.

## Poster Presentations

### Family Planning Practices Among Female Adolescent and Young Adults Living With Disabilities in Shama, Ghana

Elizabeth Adams, *Community Health Nursing Training School*

There is a belief among a sect in Ghana that having unprotected sex with female with mental health disorder or intellectual disability brings wealth (spiritual money) leading to unscrupulous men secretly sleeping with them. Females with physical and visual impairments count themselves lucky to have male sexual partners (despite their disabilities) and so have little control over sexual responsibilities leaving protection to their partners. These result in unwanted pregnancies which put extra burden on families caring for them. Some resort to abortions usually from nonprofessionals because of stigma resulting in deaths. Health promotion activities seldom target people with disabilities. Adolescents and adults with disabilities are usually excluded in sex education programmes. Every year, about 3.9 million girls aged 15–19 years undergo unsafe abortion. Increasing the use of contraception by adolescent at risk of unwanted pregnancies would avert 2.1 million unplanned

births, 3.2 million abortions, and 5,600 maternal deaths yearly. This article explores knowledge on contraception among female adolescent and young adults with disabilities, their patronage, accessibility, and the best way to reach them with contraception using qualitative methods. Female adolescent and young adults living with disabilities are sexually active and need access to contraception. There is limited research into contraceptive use of such group. Effective interventions include education on sexual and reproductive health, targeting them in the communities, involving community leaders and enforcing law on sex with persons with intellectual disability.

### Assessing the Acceptability of Using Patient Portals to Recruit Pregnant Women and New Mothers for Research

Sara Andrews, *RTI International*

Angela Gwaltney, *RTI International*

Danielle Toth, *RTI International*

Lisa Gehrtland, *RTI International*

With the advent of electronic health records, patient portals (PP) have become an increasingly common conduit for patients to access their health information and communicate electronically with their providers. PPs may also provide a novel approach for sending research recruitment invitations to potential participants. As a younger population with frequent medical visits, pregnant women and new mothers fit the profile of PP users. In this study, we evaluated the research recruitment preferences of this population, including the acceptability of using PPs for recruitment and perceived facilitators and barriers of various recruitment methods (e.g., letter, social media, PP). We conducted two focus groups each with pregnant women ( $N = 16$ ) and new mothers ( $N = 16$ ). To frame the discussion around a relevant research topic, we presented participants with sample recruitment messages for Early Check, an actively recruiting study in North Carolina that offers free voluntary newborn screening for conditions that are not on the state newborn screening panel. Following a moderated discussion, participants completed an activity in which they rated their comfort with a list of recruitment methods on a 7-point Likert-type scale. Focus group transcripts were coded and analyzed using directed content analysis. The results of the Likert activity supported focus group findings. Participants were receptive to receiving research invitations through their PP and in fact said that they found the PP more “legitimate” than most other options. Patient portals are a promising and innovative way to recruit for maternal and child health research studies.

### Identifying as Transgender and Participating in a Non-Affirming Religion

Rachael Babcock, *Athabasca University*

I conducted a literature review that highlighted the gaps in literature regarding transgender and gender nonconforming (TGNC) individuals. Although TGNC individuals are generally lumped in with lesbian, gay, and bisexual (LGB) individuals, counsellors cannot assume that their challenges are identical. While there is extensive research about internalized homophobia, which is the process of directing negative messages and stereotypes about LGB individuals inwards, and the relationship LGB individuals have with religion, there is a lack of research about how TGNC individuals navigate this complex relationship. I intend to use a transformative participatory action research (PAR) method that entails collaboration with participants as co-researchers as opposed to research on the TGNC population, in order to contribute to the current knowledge base about the intersection of religion and gender identity. Using this PAR method will allow the TGNC community to speak directly to their own experience and engage in a collective, self-reflective inquiry. Because the TGNC community is marginalized, it is essential that their voices be heard and that they remain active in facilitating the change that will affect them. A transformative PAR approach will give voice to this marginalized population and give them the space they are often not afforded to express their concerns, mental health needs, and life experiences.

### **Understanding Mental Models: Improving Specialty and Primary Care Integration**

Tanya Barber, *University of Alberta*

Lynn Toon, *Accelerating Change Transformation Team—Alberta Medical Association*

Kylie Kidd Wagner, *Accelerating Change Transformation Team—Alberta Medical Association*

Lee A Green, *Department of Family Medicine, University of Alberta*

Improving integration between primary and specialty care in Alberta is a key strategy for reducing unnecessary hospital admissions/readmissions, medical errors, delays in receiving care, and poor patient outcomes. Finding scalable improvements in integration requires understanding the lens through which specialists and primary care physicians make sense of the referral and consultation process; how they understand, think about, and approach the work they do; and their concepts of what actions produce what consequences under what conditions. Eliciting this knowledge allows us to look for differences and common traits that assist in creating more successful integration processes and transformational supports. Cognitive task analysis (CTA) is specifically designed to elicit such knowledge. In particular, the critical decision method provides insight into how decisions are made, in this case sending or accepting referrals. Using this method, we conducted a pilot project with three family physicians, three specialty physicians, and three team members. We found there is a high degree of

cognitive effort involved by both specialists and family physicians in how they approach and work within the referral process. The demand on cognitive workload is in response to identifiable factors, and this novel insight needs to be addressed if scalable improvements are to be made. Restructuring the referral process to facilitate systematic coordination is required. CTA enabled us to discover a principal issue that had not been previously highlighted by other regional studies examining the referral and consultation process. Time taken to address this issue is needed to support integrated care transformation in Alberta.

### **Examining the Influence of Community Context on the Development of Foundry Centres: A Multiple Case Study Based on Community Coalition Action Theory**

Mai Berger, *University of British Columbia*

In response to systemic gaps in mental health and substance use services for youth, community-based integrated youth services (IYS) have gained momentum as new models to improve access to care. While the general concept of IYS is well documented, different models have emerged based on community needs. Using a multiple case study approach, this master's research aims to understand how domains of community context influence the development of IYS by examining the experiences of two community-based IYS operating under the "Foundry" initiative (<https://foundrybc.ca/>). In the first stage, a secondary analysis of ethnographic data (46 interviews and five focus groups across sites) collected for the developmental evaluation of Foundry's proof-of-concept period (2016–2018) was conducted. Borrowing from community coalition action theory, the contextual domains examined were history of collaboration, geography, community demographics and economic conditions, community politics and history, community norms and values, as well as other domains uncovered with inductive analysis such as community readiness. The results of the secondary analysis informed semi-structured interviews with community members (6 across sites) working in the IYS. Cross-case analyses were conducted with framework analysis to identify how contextual domains influenced various developmental processes and structures of each IYS. The long-term goal of this research is to inform emerging evidence-based practices of IYS that are flexible and adaptable to each community's unique social, cultural, and health needs. While this research was conducted within the context of the Foundry initiative, it has the potential to be adapted by other models of community-based IYS.

### **Family Practice Physicians' Acceptance and Use of a Replacement Electronic Medical Record System: An Instrumental Case Study**

Diana Berich, *University of Phoenix*

Joann Kovacich, *University of Phoenix*

The aim of this qualitative instrumental case study is to understand how family practice physicians decide to accept and use a replacement electronic medical record (EMR) system to better prepare for future EMR changes. The passing of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 assisted in increasing implementation of EMR systems in the United States; however, technology has a short life span, and many of these initial systems need upgrading or replacement. Transitioning EMR systems have different challenges than transitioning from paper. Studying how family practice physicians process the need for upgrading their EMRs may help to better understand some of the potential drivers and challenges of individual acceptance and use of ever-changing technology in the field of Health Information Technology (HIT). The unified theory of acceptance and use technology (UTAUT) and transitions model provides the underlying theoretical framework. Semi-structured interviews of 10 family practice physicians explore the emotional and decision-making processes to accept and use a new EMR system as well as identify challenges faced. NVivo Pro 12 computer software assists with the analysis of semi-structured interviews, questionnaires, and project meeting minutes to identify themes. The study findings may be important to health care leaders, system implementers, and policy makers in understanding how future technological advances will be accepted and used by family practice physicians.

### **Rare-Diseases Patient's Motivations to Belong to Patients Support Groups in Chile**

Margarita Bernales, *Pontificia Universidad Católica de Chile*

Francisca Manríquez, *Pontificia Universidad Católica de Chile*

Rare diseases diagnosis and treatment represent a challenge for health systems and patients, given their economical, technical, physical, and emotional cost. In most cases of rare diseases, patients create groups in order to emotionally support each other during the health disease process as well as to share information. The aim of this study was to describe the motivations of patients to belong to patients support groups in Chile. Using narrative approach, a qualitative study was carried out with 30 rare diseases patients who belong to patients groups. Semi-structured interviews were delivered, achieving saturation of themes. The findings consider three thematic axes: (1) identity, (2) visibility, and (3) benefits. According to participants, being part of a patients group allows them to identify with others and support each other. At the same time, within the group, they look for ways to make their illness visible to the world and not feel like "I'm the only one this happens." Additionally, they are constantly organizing different methods to raise money to pay for high-cost treatments. Support group membership appears to be an important experience for patients, which should be promoted by health teams and incorporated as a strategy in the

interventions designed to approach rare diseases. Usually in Chile, health systems focus on the economic coverage of rare diseases, giving priority to economic and epidemiological studies that allow planning interventions; from this study, it is possible to establish that a qualitative approach could complement those approaches, providing results about the subjective experience of patients.

### **The Lived Experience and Perceptions of Nursing Students' Learning in a Concept-Based Curriculum: A Proposed Study**

Josie D. Bolianatz, *University of Manitoba*

Wanda M. Chernomas, *University of Manitoba*

With increasing healthcare knowledge, nursing education faces the challenge of content saturation where overcrowded curricula create teaching and learning environments that are focused on memorization rather than on students learning to apply information in context. In response, the faculty at a large midwestern university are delivering a concept-based curriculum (CBC) which emphasizes critical thinking and knowledge application. According to Wenger's Social Theory of Learning, the sensitizing framework for this study, curricula do not design learning, rather learning occurs as students respond to the environment. This poster presents the proposal for a hermeneutic phenomenology study that explores students' lived experiences to elucidate what it means to learn the nursing profession in a CBC. Purposeful sampling will be used to recruit six to eight nursing students who are in the first term of their fourth or last year of the program. Students will be recruited to participate in one to two individual semi-structured interviews. Data sources will include transcribed interviews, a reflective journal, and field notes. Data analysis will be guided by the principles of phenomenological reflective analysis where researchers consciously acknowledge their preunderstanding as they make interpretive sense of the data by fluidly moving from parts to whole. Rigour will be approached through reflexivity and by creating an audit trail that details how the meaning of learning was found from the participants' lived experiences. Gaining a deeper understanding of what it means to learn the nursing profession will support educators in aligning the intentions of curricula with students' perceptions and behaviors.

### **Understanding How the Law and Advance Care Planning Intersect: Considerations for Health Care Providers**

Cari Borenko Hoffmann, *Athabasca University*

Karen Cook, *Athabasca University*

Kate Leslie, *Athabasca University*

It is estimated that 30% of Canadians receive medical interventions that do not align with their wishes. Research indicates

engaging in advance care planning (ACP) processes help ensure patients' wishes are known and followed. Additional benefits include fewer life-prolonging interventions and hospital admissions which decrease system costs, better patient–family–clinician communication resulting in improved quality of life for the patient and fewer complicated grief outcomes for family members. Despite the benefits of ACP and health care organizations resource investment to ensure its uptake, barrier persist and clinicians are challenged to include ACP in their practice.

A rarely explored issue in the literature is the impact of clinicians' understanding of legal requirements and obligations as it relates to ACP. I will be conducting a case study to explore health care providers' (HCP) understanding of legal requirements and obligations imposed by BC law throughout the ACP processes, identify key factors that contribute to implementation challenges and offer recommendations. Using a qualitative case study approach, this research will seek to understand how the obligations imposed by the law contribute to HCPs' ability to support patients and families through ACP processes. This study will be guided by the Theoretical Domains Framework (TDF) which has been used in previous ACP research.

This study will build upon previous research conducted in Australia and be the first in BC and Canada to provide insight into the impact on patients and families when clinicians lack understanding of how the law and ACP intersect.

### **Understanding Patient use of Compression Garments in the Management of Postural Tachycardia Syndrome**

Kate M. Bourne, *Cardiac Sciences, University of Calgary*

Satish R. Raj, *Cardiac Sciences, University of Calgary*

Mary Runte, *Dhillon School of Business, University of Lethbridge*

Postural tachycardia syndrome (POTS) is a form of orthostatic intolerance that primarily affects women. Patients are frequently prescribed compression garments to manage symptoms, but little is known about their experience with this treatment. An exploratory descriptive–interpretive study of patient experiences will begin to address this gap.

Interviews of female POTS patients ( $n = 12$ ) explored the variables influencing compression garment use. All participants had tried compression garments, and frequency of use varied from occasional to daily.

The interviews were transcribed, and key points of intersection between benefits and challenges were then explored as they related to emerging themes of physical, social, and financial factors influencing use. Physical benefits included reduced limb swelling and fatigue as well as improved orthostatic tolerance and concentration. Physical discomfort including temperature and pressure of the garment on the body was reported as deterrents to use, and many participants reported the challenge of putting on the garment as a limitation. Garment

appearance causing social stigma and emotional discomfort was also a factor in day-to-day decisions about wearing compression: Some participants reported they purchased garments based on appearance or wore clothes to hide the garments. Garment cost discouraged use. Most participants engaged in personalized cost-benefit analysis to determine use. For one participant, risk of fainting in public outweighed the physical discomfort and unpleasant social interaction experienced while wearing the garment. Generally, participants were more likely to continue using the garment if they experienced a benefit; however, compliance with physician orders influenced continued use despite not experiencing benefits.

### **Exploring the Process of Implementing Bedside Shift Report**

Kim Brownjohn, *Providence Health Care*

Sally Thorne, *School of Nursing, University of British Columbia*

Martha Mackay, *School of Nursing, University of British Columbia*

Maura MacPhee, *School of Nursing, University of British Columbia*

Nursing bedside shift report (BSR) is a patient- and family-centred care nursing practice increasingly being adopted by healthcare institutions. BSR is the exchange of patient information between nurses with the inclusion of patients and their families. A review of the literature revealed that the implementation of BSR can be a challenging process. A majority of reports focused on the experiences of implementing BSR on single units or at single institutions. The purpose of this study was to explore what can be learned about optimizing the implementation of BSR, at various health care institutions, from the perspective of nurses who have implemented it. Nine nurses were recruited from four Canadian hospitals and interviewed using an interpretive description methodology. Two main themes and corresponding subthemes were identified in this study: (a) strategies for implementation (creating a BSR implementation working group, group member preparation, creating staff awareness, staff education sessions, and the initiation of BSR) and (b) BSR implementation challenges (attitudes and beliefs about BSR, dissemination of patient information and confidentiality concerns, the impact of changing practice to BSR, and nurses' negative influence on BSR). Nurses resisted the implementation of BSR due to the interruption of familiar practice norms, and the process was found to be further complicated by problematic relational dynamics. These findings suggest that methods for implementing BSR need to be carefully considered prior to beginning the process. Further research exploring the meaning of nursing handover and perspectives on relational dynamics in nursing may provide further insight.

## **The “Sticky Notes” Method: Adapting Interpretive Description Methodology for Team-Based Qualitative Analysis in Community-Based Participatory Research**

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Community-based, participatory research (CBPR) has a long history within HIV research, yet little work has focused on approaches to facilitating collaborative analysis within CBPR teams. We present a participatory analysis process used in a study examining the impact of a supportive housing facility for people living with HIV (PLHIV) on depressive symptoms. Sally Thorne’s qualitative methodology, Interpretive Description (ID), explicitly seeks to inform applied practice and is appropriate for identifying how supportive housing may affect depressive symptoms among PLHIV. Our team adapted Thorne’s ID to conduct team-based analysis of qualitative interview data involving Peer Research Associates (PRAs). PRAs and researchers identified categories of data most relevant to the analysis to create a colour-coded system of “sticky notes.” Sticky notes were used to record, visualize, and communicate emerging insights over the course of 11 in-person participatory sessions. Data fragmentation strategies (brainstorming, note-taking for and with others, and independent data extraction) were employed in an iterative 4-step process that was reached by consensus. During synthesis, the team created and recreated mind maps of the 969 sticky notes from which we developed categories and themes through discussion. Collaboration between PRAs during analysis resulted in rich data generation as PRAs’ similar and disparate life experiences created team synergies that propagated data cocreation. An interactive, team-based approach was central to data cocreation and capacity building, while the “sticky note” system provided a tangible, interactive method for analyzing data that facilitated a team-based analysis through visualization of the relationships between data points.

## **Qualitatively Synthesizing Broad and Diverse Literature: A Proposed Blending of Approaches to Conducting Literature Review**

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A broad literature review exploring themes and discourses in paramedicine was recently undertaken to inform a white paper on the future of the profession. Existing approaches are limited in specifying how to qualitatively summarize and synthesize a large set of diverse peer-reviewed and grey literature, encompassing a broad topic and time period. A novel approach combining methodological elements from systematic and scoping reviews, content, and discourse analysis was developed. This involved (a) searching: A systematic search was conducted using typically structured search terms and databases. (b) Selection: A ranking structure was developed to identify a representative sample of journals, weighing journal aims and scope, number of articles returned per journal, relevance to paramedicine, journal impact factor, and country of publication. Articles meeting inclusion were stratified into systematic clusters of 2-year increments. A random sample of articles from these clusters informed the analysis. (c) Analysis: Thematic coding began as article titles were reviewed and served as the foundation for subsequent full-text coding. Full-text articles were reviewed in each cluster until saturation (i.e., no new concepts, themes, or discourses were identified). To both describe the data and explain the meaning and context, analysis methods comprised sequential qualitative content analysis and critical discourse analysis, inspired by a Foucauldian framework. Literature reviews involving large and diverse data sets may benefit from the blending of methodological approaches to provide a meaningful and representative narrative, including a rich understanding of the way concepts in the literature developed over time, and in what context.

## **Knowing What to Tell: Using Simulation to Enhance Nursing Students’ Clinical Handover Communication**

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Adequate and effective communication during clinical handover has been identified as a requirement for safe practice. Identify, Situation, Background, Assessment, and Recommendation (ISBAR) is a powerful tool that can improve communication and the quality of handover. Using simulation, nursing students can adopt ISBAR in clinical handover to create a clear clinical picture of the patient. The objective of this study is to explore the development of critical thinking and communication skills by nursing students in a simulated setting. A qualitative descriptive method was adopted. Five focus group interviews were held with 8–16 Year 3 nursing students (total 64) who had attended a simulation workshop. The nursing students shared their perceptions of the simulation experience. These perceptions were collected and analyzed for common themes.

Three themes emerged that related to the simulation sessions: briefing, simulation exercise, and debriefing. The nursing students experienced “briefing: preparation is important,” “simulation exercise: doing is better than listening,” and “debriefing: methods to communicate.”

The findings enrich our understanding of how nursing students develop communication skills in a simulation setting. This study provides valuable information on designing inter-professional simulations to enhance team communication.

### **Nurses' Perceptions of Difficult Patients and Coping Strategies Used During the Management of Difficult Patients in Medical–Surgical Wards**

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Choo Jie Ling, *Raffles Hospital*

A “difficult patient” is one who engages in undesirable actions which include (i) aggressive, verbal and nonverbal; (ii) uncooperative; and (iii) demanding behaviours. Encounters with difficult patients can negatively affect nurses’ emotional health, affecting their work performance, leading to impaired nurse–patient relationships and patient care. While there have been few programs to equip hospital staff for such situations, as encounters with difficult patients, especially aggressive ones, increase over the years, it is imperative to explore and better understand the experience of nurses with difficult patients and coping strategies that have been utilized. Such information would be valuable in improving existing coping strategies, which could be shared amongst other nurses and facilitate their management with difficult patients. This study aims to explore nurses’ perceptions of difficult patients and coping strategies used during the management of difficult patients in medical–surgical wards in Singapore. A face-to-face semi-structured individual interview was conducted. Ethical approval was obtained. Purposive sampling technique was adopted to develop the sample by selecting 16 registered nurses. This study has revealed the perceptions of nurses on difficult patients, difficult patients’ impact on nurses, nurses self-coping strategies, their perceived support systems available, and challenges faced and suggestions for improvement. There were several aspects which were lacking in terms of organizational support for nurses; hence, improvements could be made to facilitate nurses’ management of difficult patients in the future.

### **Nursing Narratives and Reflective Practice: A Theoretical Review**

Ana Choperena, *University of Navarra*

Begoña Errasti-Ibarrondo, *University of Navarra*

In the context of a theoretical review, the aim of this study was to explore the literature regarding how nursing narratives had

been used to enhance reflective practice. A literature search from 1990 to 2017 was conducted in PubMed, CINAHL, and PsycINFO databases. After applying the selection criteria, 13 studies were identified. The quality of articles was evaluated. Three themes were identified as the main components of an ongoing narrative process based on looking back to past clinical experiences, creating spaces for dialogue and bringing the worlds of theory and practice closer together. In conclusion, this review provides a forum for exploring the use of narratives to enhance reflective practice, which may lead to the acquisition of professional competences.

### **Colorectal Cancer Patients' and Caregivers' Views on Self-Management in the Post-Treatment Period: A Qualitative Study**

Colleen Cuthbert, *University of Calgary*

Brenda Hemmelgarn, *University of Calgary*

Winson Cheung, *University of Calgary*

Research has highlighted that self-management (SM) has the potential to help with the complex challenges of survivorship. Little is known about colorectal cancer (CRC) patients’ views or preferences for SM in the post–cancer treatment period. To address this, we conducted a qualitative study with CRC patients and their caregivers who had completed treatment within the last 5 years. Data were gathered using focus groups and individual interviews which were recorded and transcribed. Interpretive description was used to guide data analysis and interpretation of results. We included  $n = 19$  patients and  $n = 3$  caregivers. The mean time since diagnosis was 3.2 years. Results of the study revealed that participants were keen to engage in SM behaviors as they saw it as being proactive for their health, yet they needed more support as evidenced in the following themes: (1) Survivors need more structured ways to engage in SM, (2) finding information and support was often haphazard, (3) information and support to manage the long-term physical and psychological consequences of treatment are needed, (4) peer support would help normalize survivorship, (5) sexual health and bowel changes are particularly challenging, (6) health care providers should encourage healthy behaviors, and (7) information and access to programs for healthy behaviors are needed. Aligned with Interpretive Description’s emphasis on informing clinical practice, we highlight the following: (1) CRC patients are keen to take control of their health and well-being through SM and (2) health care providers and cancer systems should support SM to ensure optimal recovery in the posttreatment period.

### **Responses to Gene-Based Personalized Nutrition Information Among Individuals With and Without Depressive Disorders**

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Paula Littlejohn, *University of British Columbia*

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Annie Tsang, *Kwantlen Polytechnic University*

While studies suggest that gene-based personalized nutrition (GBPN) information has the potential to contribute to disease prevention and treatment, little is known about its uptake, particularly among clinical populations. Using thematic analysis, we compared interview data, one set from a general sample ( $n = 55$ ) and the other from individuals with depressive disorders ( $n = 28$ ), from two GBPN efficacy trials. Both groups indicated their interest in study participation was to have readily available access to their gene-based information. Individuals from the general sample cited their main goal was to improve health, and many wanted to lose weight. However, the main interest among the sample with depressive disorders tended to be specific to their health condition and a desire to improve symptoms. Both groups indicated they found the information to be motivating, though somewhat technical. Furthermore, they acknowledged that without assistance from a health professional, it would be difficult for them to integrate the results into daily practice. Several from the general sample stated that, in addition to dietary changes, they increased their physical activity levels. Both groups identified positive outcomes such as eating healthier; however, those with depressive disorders tended to highlight improvement in their mental health and cognition. These findings suggest that diverse groups are likely to adopt GBPN but for different reasons. Furthermore, there is variability in terms of what people perceive as positive outcomes. Although GBPN is currently not part of conventional healthcare, practitioners should be aware of the widespread consumer interest and consider developing best practices for diverse populations.

### **Roll of Parenting in the Treatment of Childhood Obesity in Low-Income Families From Mexico City**

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Ericka Ileana Escalante Izeta, *Universidad Iberoamericana, campus Puebla*

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Childhood obesity is a serious public health problem in Mexico due to its high prevalence and biopsychosocial impact. In the present study, we used grounded theory to understand the relationship between psychosocial categories associated with the evolution of childhood obesity in low-income families from Mexico City. We conducted 24 in-depth interviews with 12 families with children with obesity, before and after participating in a psycho-nutritional intervention with art therapy that we previously designed. We use NVivo for the qualitative content analysis. We found that the participating families are permissive, poorly structured, and have difficulties in establishing

norms and limits that regulate child food and leisure behavior, reinforcing their emotional eating strategy. After taking the workshop, the participating families showed positive changes in the categories: subjectivity and parenting practices and child behavior. These changes, such as the illness perception, insights about their lifestyle, the development of creative strategies for child regulation, and increased motivation, among others, stimulated a healthier lifestyle. In addition, we obtained significant quantitative improvements in the eating practices, self-efficacy, and waist-height index of the children. We conclude the importance of improving parenting practices in addressing childhood obesity, as well as the positive effects of the psycho-nutritional intervention designed, by facilitating a group space for support, learning, motivation, and insights throughout the creative techniques.

### **Radical Feminist Understandings of the Handmaid's Tale**

Andrea Dekeseredy, *West Virginia University*

Patricia Dekeseredy, *West Virginia University*

Walter Dekeseredy, *West Virginia University*

The number of shows illustrating feminist theories pales in comparison to those that embody mainstream offerings, particularly those that emphasize psychological ways of knowing. One salient departure from this norm is *The Handmaid's Tale*. Aired on Hulu and based on Canadian author Margaret Atwood's best-selling novel, this series has what Rafter and Brown refer to as "the ability to engage with multiple perspectives." Radical feminists contend that the most important set of social relations in any society is found in patriarchy and that, throughout the world, females are the most oppressed social group while, regardless of their race/ethnicity and social class, men always have more power and privilege. *The Handmaid's Tale* deviates from a strict radical feminist interpretation by demonstrating "power within and between" women in the series and in Atwood's book. The aunts who train handmaids and the commanders' wives have much more power in Gilead than do handmaids and the Marthas who serve as wives' servants. All the women in the series have little power relative to men, but there is a constant struggle of power between these different groups of women. *The Handmaid's Tale* is helping to mobilize worldwide movements aimed at successfully challenging patriarchy and other forms of inequality such as capitalism and racism. We explore this show as a valuable pedagogical resource and how it can be used to illustrate radical feminist perspectives on crime, justice, and a host of contemporary social problems.

### **Exploring Resident Wellness and Stress Management Strategies**

Patricia Dekeseredy, *West Virginia University*



**Cara L Sedney, West Virginia University**

**Sarah Helen Sofka, West Virginia University**

Wellness is a broad term consisting of the multidimensional aspects of one's life that in combination lead to optimal levels of health, emotional, and social functioning. It is important to foster a culture of wellness during medical education especially since residents experience high rates of burnout and depression which can negatively impact their personal and professional lives. The American Medical Association outlines six aspects that are key for resident well-being. These include nutrition, fitness, emotional health, preventative care, financial health, and mindset and behavior adaptability. The West Virginia University's School of Medicine has approximately 410 residents in 20 core programs, and instruction in well-being is an integral part of their ongoing curriculum. However, this education is developed and integrated by each individual program creating many interpretations of how this curriculum should be delivered. In addition, residents also have access to employee assistance programs and other general wellness initiatives offered to hospital employees. This exploratory, qualitative descriptive study used semi-structured interviews to investigate the experiences of residents recruited through a resident wellness survey. Findings describe the impact their experiences had on their physical and mental well-being and illuminate factors that could contribute to improving overall wellness among residents during their medical training. This information is important in order to better understand the current state of wellness among the residents, to target interventions, and evaluate current self-care initiatives. This study contributes to the growing body of knowledge on workplace mental health for students and employees in a healthcare environment.

### **Developing a Nurse-Focused Educational Intervention for Moral Distress**

**Sadie Deschenes, University of Alberta**

**Shannon Scott, Women and Children's Health Research Institute, University of Alberta**

**Diane Kunyk, University of Alberta**

Pediatric intensive care units are highly complex, busy environments with many different healthcare professionals providing numerous forms of advanced life-sustaining care to critically ill children. These environments are ripe settings for moral distress in healthcare professionals, particularly nurses, given the nature and scope of their practice. Moral distress occurs when an individual is unable to act according to their moral judgement due to external constraints (e.g., environmental demands, pace of work, available resources) or personal factors (e.g., professional role, work responsibilities). Moral distress can result in emotional, psychological, and physical symptoms, leading to reduced job satisfaction, burnout, and poor patient outcomes. The purpose of this study is to develop an educational intervention for PICU nurses to manage morally distressing situations. Interpretive description will be used to explore key elements of moral

distress and preferences for delivery of the educational intervention. Nurses who have experienced moral distress in the PICU will be invited to participate in semi-structured interviews. Data collection and analysis will be done concurrently. A three-phase process will guide analysis. Participant perspectives will inform the content and method of delivering the educational intervention (e.g., digital tool, didactic presentation in orientation, annual competency requirements). The intervention developed has the potential to better prepare nurses for complex ethical issues in their work that may result in increased nurse job satisfaction, increased retention/recruitment rates, and improved patient outcomes. The findings of this study may be used to inform and improve how nurses are prepared for morally distressing situations.

### **Project: Qualitative Study of the Students Learning From Health Mentor Patients**

**Cristina Di Silvestre, Universidad del Desarrollo**

The ways to answer the health needs had changed from some decades up to now due to the population demographic transition. This situation had implied that the population reach more advanced age, which mean it is facing more diseases and chronic impairments joint to comorbidities. For those reasons appears the need for innovations in the health professionals' education as well as in the model of health care. In this scenario, the health education has been progressively introducing the "patient voices" given the strong evidence referring to its contribution on the students' learning and the health outcomes. In the context of innovation in teaching in health sciences and in order to place it according to experiences and health international organizations, The Health Mentor Interprofessional Program at Universidad del Desarrollo (a replica from the Health Mentor Program of UBC) is installed in 2018, as pilot phase, which aimed health sciences students to learn those absent aspects in the texts and in the formal instances of teaching. Our research question is "From the students' perspectives: what they learn about illness experience in the meetings that they have with the health mentors?" The design is an instrumental case study; the "reflexive diaries" (78 in total) will be used as data collection tool; diaries allowed collect subjective experiences from patients' lifetimes. The diaries will be content analysed. The students who participate in the program will check the data validity.

### **Struggles and Alleviations in Accessing Primary Health Care in a Multisites Organizational Participatory Action Research Study: Findings From a Qualitative Research Design**

**Emilie Dionne, St. Mary's Research Centre, McGill University**

**Cathie Scott, PolicyWise for Children & Families; University of Calgary**

In an Australia–Canada study aiming to improve access to primary health care (PHC) for vulnerable groups through organizational transformation (2013–2018), six evidence-based interventions were adapted and implemented locally. This poster presents qualitative findings from the mixed methods research protocol developed to evaluate the interventions. Composed of semi-structured interviews with providers (service providers, family doctors, nurses) and patient or attendee, these explore experiences, knowledge, and expectations of access to PHC and postintervention changes. Our findings focus on Canadian findings only. Across Canada, provider data show their desire to work collaboratively, yet what collaborative team work means remains nebulous. PHC providers also express feeling alone with patients whose needs go beyond the scope of their knowledge and expertise and “abandoned” by the system, “not knowing what the government expects of them.” Patient data report feelings of vulnerability, difficulty to trust, and fear of stigma and judgment yet strong resilience. Users feel and want to be heard and acknowledged as “people” and with knowledge and experience worthy of consideration. Finally, while two interventions addressed patients without a regular care provider at baseline, feelings of vulnerability were also present in attached patients who expressed vulnerability toward an individual sole provider who may leave unexpectedly. Postintervention data show that the interventions helped in addressing these issues; our poster reports on “how.” The poster completes an exploration of findings with lessons learnt from these three interventions, methodological design and insights, and next steps in improving access to care.

### **Using a Phenomenological Description Excerpt About the Nurse–Patient Relationship at the End of Life As a Means to Improve the Relational Competence of Nursing Students**

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Donna M. Wilson, *University of Alberta*

Ana Choperena, *University of Navarra*

The nurse–patient relationship is the essence of nursing practice. For many terminally ill people, it becomes of paramount importance as they need more than ever human accompaniment. Although the nurse–patient relationship is often addressed in undergraduate courses, the fact that it is a complex and intangible human phenomenon makes difficult for students to gain enough understanding about it, particularly in the context of end-of-life care. As such, nursing students frequently lack the opportunity to reflect on and gain insight about it, are not ready enough to establish appropriate and adapted relationships with terminally ill patients, and do not realize how significant this relationship is for them. In this context, the phenomenological descriptions may be used as timely adequate

teaching tools. Therefore, after research ethics approval, this qualitative descriptive study explored the usefulness of reading and reflecting on an eidetic theme derived from a phenomenological study that sought to describe and understand what it is like for a patient living with advanced terminal illness to have a relationship with the nurse. Thirty nursing students in Alberta read the theme and wrote reflections on it. The thematic analysis of students’ reflections revealed the text helped them: gain a more insightful and broad-based view of the importance and nuances of the nurse–patient relationship at the end of life; gain perspective on the experiences of patients in relation to the care they receive; gain awareness of their own nursing practice, attitudes, and behaviors; resolve to improve their future nursing practice; and point out how nurses should relate.

### **Ambulatory Cancer Care: A Community-Based Participatory Research Evaluation of a Novel British Young People’s Service**

Alison Finch, *Department of Applied Health Research, University College London*

Silvie Cooper, *Department of Applied Health Research, University College London*

In the United Kingdom, around 2,400 teenagers and young adults (TYAs) aged 13–25 years are diagnosed with cancer each year. Dedicated hospital units for TYAs with cancer have been in place since 1991 prioritizing “age-appropriate care.” In 2012, the National Health Service (NHS) introduced ambulatory cancer care within the specialty of TYA Cancer, offering intensive, inpatient cancer treatment on an outpatient basis. Over 50 treatments are now eligible for ambulatory care, but the lived experience of the pathway, intended to promote independence and normality for TYAs, is yet to be evaluated. This poster presentation describes a doctoral research proposal in development: an action evaluation of TYA ambulatory cancer care informed by a community-based participatory research approach. Derived from conversations with young people using a card-sorting technique to explore their ambulatory experience, the evaluation has been funded by the National Institute for Health Research. It engages a TYA cancer community with experience of receiving and delivering ambulatory care in every aspect of the research process: young people, family, clinicians, academics, and national charity partners. Through interview and video ethnography, it seeks to describe the experienced reality, iteratively developing transformative knowledge and actions to (a) progress the service’s development and (b) advance our understanding of age-appropriate ambulatory care. This research will also explore the extent to which community-based participatory research, established as a research approach in North America among indigenous or marginalized communities, can engage British young people with cancer, elucidating their care needs and building their capacity as coresearchers.

## Using Google Forms in Research on Sensitive Topics

Simona Fourie, *University of Oxford*

Recruiting adolescents to sensitive research studies can be difficult, some researchers avoid sensitive issues due to difficulties surrounding regulatory approvals, recruitment, and obtaining free expression of views. Hence, data collection tools used for such studies need careful consideration to enhance participation. Health care researchers need to employ new data collection methods to be as inclusive as possible and to respond to the societal communication trends. Adolescents are more likely to share intimate aspects of their life in an anonymous manner through internet. Similarly, they value being in control of the participation to research in terms of time and space. Google Forms (GF) are generally used for anonymous surveys in some disciplines, but no evidence of data collection for narrative accounts was found. GF were used to collect sensitive narrative accounts about intimacy and sexuality issues from young women aged 16–24 years living with inflammatory bowel disease. Ensuring anonymity to the participants offered a safe haven for disclosing intimate details of their life. The narrative accounts collected via GF provided researchers with valuable data. Preliminary data collected via GF helped to develop interview protocols. It is not suggested to replace interviews with GF but use them as additional data collection method as there are limitations on the data collected due to lack of dialog between participants and researcher. We suggest that GF can have potential benefits as a data collection method in sensitive qualitative research.

## The Exploration of the Impact of Interprofessional Education: Dental Hygiene and Physiotherapy Perspectives

Moni Fricke, *University of Manitoba*

Laura MacDonald, *University of Manitoba*

Fiona Jensen, *University of Manitoba*

Robin Oliver, *University of Manitoba*

Health professional educators are infusing interprofessional education (IPE) within curricula to ensure health care providers are interprofessional collaborative care (IPCC) practitioners. To this end, a 2-year longitudinal IPCC curriculum was implemented, placing nearly 600 students from nine health professional programs into teams. The curriculum is based on three foundational competencies common to all health professions: IPCC, population health, and patient safety. Students learn with, from, and about each other through face-to-face activities and simulation; online-facilitated discussions; and a team assignment. Across the 2-year curriculum, students are required to submit individual written reflections on their experience of interprofessional team communication and functioning. Program evaluation to date has

focused on team development and individual learner responses to interprofessional socialization. Less understood is the potential difference in the lived experiences of learners from different programs. A qualitative analysis using focused ethnography was therefore undertaken by the curriculum developers to explore the perspectives of the 26 dental hygiene and 50 physiotherapy students. The local ethics board was consulted, and formal approval was not indicated for the evaluation of this curriculum. Using constant comparative analysis and researcher triangulation, five themes emerged from the learner reflections: (1) sharing expertise, (2) “the whole is better than the sum of the parts,” (3) open-mindedness, (4) breaking down barriers, and (5) finding your voice. Students moved from initially questioning the value of the IPE activities to realizing that they had changed as a result. Whether such curricula can affect sustainable change postgraduation remains unknown.

## Change, Challenge, and Excitement: Reflections on the Transition From Student to Newly Qualified Nurse

Helen Gibson, *University of Hull*

Jane Wray, *University of Hull*

The transition period from student to NQN is recognised as a period of change, challenge, and excitement. NQNs report feeling exhausted, stressed, and unconfident—all characteristics of “transition shock”. Effective preparation and support during transition are crucial for successfully managing the transition to fully autonomous practitioner (Brooks et al., 2019; Health Education England). The STaR project is a mixed-methods study funded by the Burdett Trust for Nursing that is exploring successful transition and retention of NQNs. This presentation will share the emerging themes from qualitative data captured via the directed reflections of final year, final semester nursing students and will focus on students’ perceptions of the key challenges they face and the support they felt they needed to successfully transition into the NQN role. Reflection is a well-established tool used in nurse education and practice to promote self-awareness, enhance learning, connect theory and practice and is integral to personal and professional development as a nurse. One hundred thirteen directed reflections that explored perceptions, expectations, and transition support needs were completed by two student cohorts at one university in UK. Representational text analysis was used to understand the author’s meaning. Three overarching themes emerged: personal, professional, and clinical. Personal issues included those that are related to an individual’s characteristics, personality and personal skills, and perceptions or feelings. Professional issues included status, accountability, identity, and autonomy. Clinical issues are related to the practical skills and knowledge associated with being a nurse (competencies).

## **Using a Pragmatic Approach to Understanding Meanings of Successful Aging for People Living With Long-Term Spinal Cord Injury**

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Veronica Allan, *Queen's University*

Sheila Casemore, *Spinal Cord Injury Ontario*

Teren Y. Clarke, *Spinal Cord Injury Alberta*

Advancements in rehabilitation, assistive technology, and comorbidity identification have contributed to increases in life expectancy for people living with spinal cord injury (SCI). As such, efforts to support individuals aging with long-term SCI are urgently needed. Although the concept of successful aging (SA) is used to understand aging in the general population, most SA conceptualizations exclude individuals with long-term physical disabilities. This study aimed to understand meanings of SA from the perspectives of individuals with lived experience of aging with long-term SCI. Using an integrated knowledge translation (IKT) approach, this study was conducted in equitable partnership with three SCI organizations. Aligning with IKT approaches, the research team drew upon a pragmatic paradigm to ensure the research findings were addressed through a course of action and developed into tangible recommendations. Semistructured interviews were conducted with 22 people (mean age: 55.64; mean years postinjury: 32.27). An interview guide codeveloped in partnership with three SCI community organizations was used to facilitate each interview. All interviews were analyzed through inductive thematic analysis. Three overarching themes were constructed: (1) SA is an interconnected and multifaceted concept; (2) intrapersonal, interpersonal, and environmental barriers prevent SA; and (3) your outlook, actions, and the actions of others facilitate SA. Findings from this study provide insight into what SA means for individuals aging with long-term SCI and suggest that efforts to support people aging with long-term SCI should focus on improving the quality of one's participation in society (e.g., having a sense of purpose while fulfilling a social role).

## **"It's not Simple and It's Not Straight Forward": Challenges and Opportunities in Scaling up Access of Direct-Acting Antiviral Hepatitis C Virus Treatment to People Who Inject Drugs**

Trevor Goodyear, *British Columbia Centre on Substance Use*

Lianping Ti, *British Columbia Centre on Substance Use*

Will Small, *British Columbia Centre on Substance Use*

## **Rod Knight, British Columbia Centre on Substance Use**

Recent advances in the safety, tolerability, and efficacy of hepatitis C virus (HCV) treatments have led to the introduction of policy changes that include, in some settings, universal coverage of direct-acting antiviral (DAA) treatment for people living with HCV. However, people who inject drugs (PWID), a population with disproportionately high rates of HCV, often experience a variety of social and structural barriers to healthcare. The objective of this study is therefore to identify implementation challenges and opportunities for improving HCV-related care and scaling up DAA treatment for PWID in a setting with universal coverage of these medications. Drawing on semistructured interviews with a purposive sample ( $N = 15$ ) of expert stakeholders (e.g., clinicians, community-based representatives, and policy makers) in HCV care in British Columbia, Canada, our analysis revealed two broad themes and corresponding subthemes: First, participants described challenges for scaling up DAA treatment, including how socio-structural barriers (e.g., housing, stigma) restrict opportunity for PWID to engage in care, how strained and compartmentalized health services are onerous to navigate, and how healthcare providers inequitably gatekeep access to DAAs (e.g., withholding treatment from people who actively use substances). Second, participants described opportunities for improving HCV-related care through socio-structural intervention (e.g., drug decriminalization and improved housing), enhanced models of care (e.g., decentralized, integrated, outreach-focused, and peer- and nurse-led services), and increased education for healthcare providers on evidence-informed HCV care. These findings emphasize the need for DAA scale-up and broader health policies to be equity oriented and responsive to the ways in which socio-structural determinants influence health.

## **Adherence to Medical and Medication Treatment in Ulcerative Colitis: What do Resilience and Disease Acceptance Have to Do With It? A Qualitative Study**

Ksenia Gorbenko, *Icahn School of Medicine at Mount Sinai*

Karen Conlon, *Icahn School of Medicine at Mount Sinai*

Laurie Keefer, *Icahn School of Medicine at Mount Sinai*

Previous research has shown that resilience improves a person's ability to cope with adversity, including managing chronic illness. However, little is known about the relationship between resilience and adherence to medical therapies. This study aimed to determine how resilience relates to adherence to medical therapy recommendations among patients with ulcerative colitis, a chronic gastrointestinal immune-mediated

inflammatory condition. Semi-structured qualitative interviews were conducted with patients ( $N = 16$ , 63% female, aged  $40 \pm 16$  years) who were recruited at an Inflammatory Bowel Disease Center within an urban academic medical center that provides multidisciplinary care. The interviews lasted about 1 hr. Three analysts coded interview transcripts in NVivo Version 12 using an inductive qualitative analysis approach. Our analysis showed that resilience after a diagnosis of UC was facilitated by having social support, self-confidence, optimism, and clear goals. Disease acceptance—a nonlinear, multitiered process—emerged as a mediating factor in explaining the relationship between resilience and adherence to medical therapy. We identified four disease acceptance—resilience phenotypes: (a) accepting disease without resilience (“professional patient”), (b) resilient without disease acceptance (“pushing through”), (c) resilient patients who have accepted their disease (ideal), and (d) patients with low resilience and no disease acceptance (disengaged). Our findings indicate that both resilience and disease acceptance are critical to adherence to treatment among patients with ulcerative colitis. Medical and behavioral care providers should work with patients and families to help them achieve disease acceptance and increase their resilience to establish grounds for adherence to recommended treatments. This study is sponsored by Pfizer Inc.

### **Capturing Youths’ Meaning-Making Process: A Dialogic Narrative Analysis (DNA) Approach**

Andrea Greenblatt, *University of Toronto*

Eunjung Lee, *University of Toronto*

A novel approach for honoring the voice of youth themselves and capturing the experiences of youth with mental health concerns, Dialogical Narrative Analysis (DNA), explores how multiple voices find expression within one’s narrative and how this dialogic process facilitates one’s meaning-making. DNA seeks to understand the content of participants’ subjective and collective narratives, the cultural resources used to develop narratives, and the impact that narratives have on the emergence of a sense of self. This unique, client-centered methodological approach is critical in revisiting how mental health practitioners construct professional knowledge on youth with mental health concerns. Research questions will include (1) What are the various voices in youths’ lives? (2) How do they experience and negotiate with these voices? (3) How do they make meaning of these experiences and their negotiation process? Data collection involves an iterative process focused on maintaining a participant-focused lens. Multiple modes of collection are employed given youth preference such as arts-based and journaling approaches along with in-depth interviews to facilitate youths’ reflection. Findings have the potential to inform future research based on ethical, child-focused principles as well as promote dialogue around current best practices in the area of youth mental health practice.

### **Recruitment Plan and Data Management Process For a Qualitative Study Using Photovoice**

Sama Hammad, *Imam Abdulrahman Bin Faisal University*

Lulu Almana, *Arup Company*

Hajar AlYahya, *Imam Abdulrahman Bin Faisal University*

The prevalence rate of obesity in Saudi Arabia have skyrocketed since the 1990s. The recent update from the Ministry of Health have indicated priority topics in 2019, which includes obesity and childhood wellness. Childhood obesity is particularly high in the eastern province of Saudi Arabia. One component in the obesity literature includes lifestyle factors of physical activity and exercise habits in children and their families. However, exploration of the surrounding environment in relation to obesity has yet to be studied in Saudi Arabia using photovoice method. The aim of this study is to explore families’ perspective (mothers, fathers and children [aged 6 to 19]) on what are the facilitators and/or barriers in their surrounding and built environment. The method of study will a qualitative design; first, photovoice will be used as a means to capture photos from the families’ surrounding of what constitutes as a pro-active environment and vice versa. The data collected will be photos with a sentence captioning how this is a facilitator or barrier. Second, a focus group will be arranged with the participants to further explore the photos taken. Thematic analysis of the photovoice and focus group transcripts will then follow. Third, the research team will arrange a photo exhibition presented by families and their children for crucial stakeholders. Stakeholders that influence decision and policy-making around the community’s built environment. The focus of this abstract will be on the recruitment plan and data management process of this study in consideration to the Saudi Arabian culture.

### **A Grounded Theory of Healthcare Providers’ Experiences of Awe And Practice of Compassion in Long-Term Care**

Daranne Harris, *University of Calgary*

Shane Sinclair, *University of Calgary*

Qualitative research, in the methods employed (i.e., in-depth interviewing) and topics explored (i.e., sensitive topics such as death/dying and trauma/abuse), is emotionally demanding for all parties involved. While it is common for ethics protocols to protect research participants from emotional distress, the personal impact of emotional work on the researcher can often go unaddressed. Qualitative researchers, in particular graduate student researchers studying sensitive topics, are at risk of profound psychological effects as a result of engagement with

an individual's trauma material. It is unclear, however, how this researcher impact is discussed in graduate student work and/or the steps taken to address this risk. Therefore, to provide an overview of how researcher impact is considered in Canadian graduate student research, a comprehensive scoping review of dissertations and theses was conducted. A search of student research work within sensitive topics and employing methods that posed a risk for emotional impact returned over 50,000 titles, with 562 retained for data extraction. Dissertations from 20 Canadian Universities are included in the analysis with a broad range of disciplines represented. Findings show that 81.5% of dissertations do not discuss methods to address the emotional impact of sensitive research on the student-researcher; 15.2% of dissertations describe some strategy (predominantly journaling) documenting the impact of the research and only 3.3% of dissertations had a defined protocol or plan to address the risk of emotional distress on the student-researcher. These findings suggest a need for further guidance on minimizing the risk of emotional distress among graduate student-researchers.

### **Mothers' Perceptions and Practices Related to Noncommunicable Disease Prevention in Sri Lanka: A Narrative Study**

Machiko Higuchi, *National College of Nursing Japan*

A general improvement in Sri Lanka's socioeconomic factors and the resultant increase in life expectancy have contributed to the growing prevalence of noncommunicable diseases (NCDs) including lifestyle diseases; prevention is seen as the only solution. This highlights the potential of early interventions to prevent diseases and promote health. Mothers in Sri Lanka are unaware of not only their children's health behaviour regarding prevention of NCDs but also their own. This study aimed to clarify mothers' perceptions and practices related to NCD prevention after attending an integrated maternal and child health programme. We conducted focus group interviews according to a semi-structured interview guide to collect data from 15 mothers who participated in the NCD prevention programme in Western Province, Sri Lanka. The interviews were transcribed verbatim, and the data were coded thematically. Most mothers could identify that NCDs included diabetes mellitus, hypertension, and high cholesterol, while a few believed that NCDs included dengue fever, animal-borne infectious diseases, and genetic diseases. A majority of mothers expressed the importance of proper exercise; lower oil, sugar, and junk food consumption; and good sleep quality as ways of preventing NCDs. They reduced their own sugar, oil, salt, and flour intake after participating in the programme. They also tried to avoid eating late and heavy dinners and emphasised that they imparted the knowledge they acquired to their family members. Further research is required to identify hindrances encountered by mothers in building their knowledge and practices related to NCD prevention.

### **Assessing the Capacity of the Ethiopian Public Health System in Using Evidence in Policy and Decision Making**

Sarah Hurlburt, *T.H. Chan School of Public Health Fenot Project, Harvard University*

There is growing interest in the Ethiopian public health system to improve the use of evidence in decision making and policy development. Understanding the current status of the health system's ability to promote the use of data in decision making is a necessary input to improvement efforts. Organizational capacity, climate, and culture, in addition to individual skills, have been shown to be important determinants of how effectively and widely evidence is utilized in policy making. The Organizational Research Access, Culture, and Leadership (ORACLE) tool is a 23-question interview guide to be applied with the leadership of policymaking organizations. ORACLE is a measurement tool designed to create valid, reliable, theory-based measurement of organizations capacity to use research in policy development. The Fenot Project, of the Harvard T.H. Chan School of Public Health, has been working to support the Ethiopian Ministry of Health (MOH) and Regional Health Bureaus (RHBS) to improve the use of evidence in policy making for the last 3 years. The Fenot project applied the ORACLE tool with a directorate of the Ethiopian MOH and two regional health bureaus. After applying the tool, a summary report of the responses to the assessment as well as a score for each of the 23 questions was generated for each institution. The quantitative findings from the ORACLE assessment in the MOH showed that the Directorate is performing at about 69% of its potential to support the use of evidence in program and policy decision making. The RHB's performance was considerably lower. Results of the assessment will be shared along with recommendations for actions to be taken to improve the capacity of the Ethiopian health system to integrate greater use of evidence in policy and program decisions.

### **Lets Talk About Sex! Health Care Professionals' Experiences Facilitating Sexual Health Education With Adults With Acute Coronary Syndrome**

Emily K. Hyde, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Donna E. Martin, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Kendra Rieger, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Reece Malone, *Sexuality Consultants and Support Services, Manitoba Inc*

Each year, 63,000 Canadians are diagnosed with acute coronary syndrome (ACS) with a 73% survival rate. Although sexual

health education is clearly indicated in several key clinical practice guidelines for adults with ACS, researchers have found that health care professionals rarely provide sexual health education to this patient population. Lack of knowledge about sexual health post-ACS results in increased fear, depression, and anxiety among ACS survivors. The purpose of this qualitative study is to explore healthcare professionals' experiences facilitating sexual health education with ACS survivors in cardiac rehabilitation (CR) programs in a Western Canadian province. The research question is "What are CR healthcare professionals' experiences facilitating sexual health education to ACS survivors?" The study design is an interpretive description with a guiding framework of sex positivity. Using purposive sampling, licensed healthcare professionals with a minimum of 1 year experience in CR will be invited to participate using an invitational email letter and poster at the CR sites. The goal sample size is 10–15. One-hour, face-to-face, semi-structured, digitally recorded interviews will be conducted. Digital recordings will be transcribed verbatim. The first author will document theoretical and methodological insights in a reflective journal. Data will be analyzed using constant comparative analysis. This study is significant in that the findings may inform CR healthcare professionals about educational strategies that promote sexual health and psychosocial well-being among ACS survivors.

### **Exploring Somali Refugee Women's Experiences Accessing Health Care Services in Manitoba**

Anisa Isse, *College of Nursing, University of Manitoba*

Lynn Scruby, *College of Nursing, University of Manitoba*

Donna Martin, *College of Nursing, University of Manitoba*

In 2012, there were significant cuts to Canada's Interim Federal Health Program, an extended health insurance program for newcomer refugees. The cuts resulted in inequitable access to funding amongst government-assisted refugees, privately sponsored refugees, and refugee claimants. The funding was restored in 2016; however, policies that differentiate access to health care based on refugee status continue to exist. This exploratory qualitative descriptive study recruited a purposive sample of Somali women who were government-assisted refugees ( $n = 3$ ), privately sponsored refugees ( $n = 6$ ), or refugee claimants ( $n = 3$ ) and were residing in Manitoba, Canada. The theory of well-being in refugee women experiencing cultural transition was used to guide the study. The principal investigator used a semi-structured interview guide to inquire about each woman's experiences accessing and utilizing health care services in Canada in individual, face-to-face, digitally recorded interviews. Five of the 12 interviews were conducted in English, and the remaining 7 interviews were conducted in Somali and were translated into English and then transcribed by the principal investigator. Qualitative content analysis was used to analyze

the data. The findings are presented in three sections: accessing health care, utilizing health care, and the role of the health care provider. The results of this study support the findings of previous research and problematize current refugee health care delivery in Manitoba. The refugee claimant women experienced the most significant challenges in accessing and utilizing health care. This timely study has implications for health care providers, professional health program educators, and policymakers.

### **The Family Experience of the Autism Spectrum Disorder Diagnostic Conference: A Meta-Synthesis**

Alexandra Jackman, *University of Alberta*

Shanon Phelan, *University of Alberta*

Lonnie Zwaigenbaum, *University of Alberta*

Lisa Tjosvold, *University of Alberta*

Autism spectrum disorder (ASD) is a neurodevelopmental condition with impairment in social communication and restricted, repetitive behaviours and interests present from childhood. The Canadian prevalence of ASD is approximately 1 in 66 children, and increasingly, clinicians are responsible for discussing new ASD diagnoses with families. Current guidelines for ASD diagnostic communication highlight the importance of a timely in-person discussion, sensitivity, and "recognized good practice." However, there has not been a systematic review of families' experiences to guide the communication framework. Research indicates that receiving the initial ASD diagnosis is a profound and often negative experience for families. Given the critical importance of this process, the purpose of this qualitative meta-synthesis is to better understand the family experience of an ASD diagnostic conference. Drawing on Sandelowski and Barroso's approach, we conducted a systematic search to capture published and unpublished literature, all qualitative study designs, and qualitative components of mixed methods studies. We are finalizing selection of studies for inclusion and will develop a flow diagram of studies according to Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. Applying Saini and Shlonsky's method, the "Findings/Results" sections of included studies will be coded by two independent reviewers. Themes will be developed by an interdisciplinary team of two to five reviewers applying an inductive and iterative process, then aggregated to form an overall synthesis of meaning, aiming to describe and appreciate the family experience of the ASD diagnostic conference. This meta-synthesis may inform individual clinician practices, medical education around communication, and family-centered care policies.

### **Employment-Related Decision Making for Patients With Cardiac Arrhythmia**

Shannon Jarvie, *Dhillon School of Business, University of Lethbridge*

Kelly Williams-Whitt, *Dhillon School of Business, University of Lethbridge*

Mary Runte, *Dhillon School of Business, University of Lethbridge*

The experience of patients with cardiac arrhythmia is seldom explored from the perspective of the patient. This descriptive interpretive study uses sensemaking as a framework of data collection and analysis, to examine the processes, procedures, and activities that individuals undertake while navigating the unfamiliar path of maintaining employment, seeking workplace accommodation or otherwise modifying their employment following the emergence of symptoms or the diagnosis of A-fib or sudden cardiac arrest. Patients ( $n = 20$ ) will be recruited from participants in an ongoing study of patient experience of cardiac arrhythmia and will purposively be selected on the basis of their having been employed while engaging in care for their arrhythmia. Semi-structured interviews will explore the sensemaking process that is (1) grounded in identity construction, (2) retrospective, (3) enactive of sensible environments, (4) social, (5) ongoing, (6) focused on and by extracted cues, and (7) driven by plausibility rather than accuracy.

### **What Do the Family Medicine Trainees Experience During the Hospice Palliative Care Training?**

Hyun Jung Jho, *National Cancer Center*

Jwa-Seop Shin, *Department of Medical Education, Seoul National University College of Medicine*

Hospice palliative care (HPC) aims to improve the quality of life for patients with incurable illnesses and their families. Therefore, HPC training for family medicine trainees focuses on a holistic approach including pain and symptom management, psychologic support, communication with patients and family members, terminal care, and a team approach. These characteristics are different from what the trainees usually experience in “acute care setting,” where diagnosis and treatment of disease are main aspects of training. Current HPC training curriculums have objectives to equip the trainees with appropriate knowledge, skills, and attitudes on HPC. However, the training is seldom evaluated in depth from the perspective of the trainees, such as what they experience, perceive, and what influences such experiences. Therefore, this study is going to explore the experiences of family medicine trainees toward HPC training. Researchers will conduct a semi-structured interview for family medicine trainees who underwent HPC training program. The interview questions will include “What did you experience during the HPC training?” “How did you perceive that experience?” and “How did the experience affect your practice?” The interview records will be analyzed using a phenomenological approach to describe the HPC training experience from the perspectives of the trainees.

Furthermore, the data will be interpreted to describe what affect the training experience, based on the theories on participatory practice for medical trainees, specifically, identifying individual factors linked with learning (e.g., personal epistemology, engagement), external factors (e.g., affordance), and interactions of these factors.

### **Bereavement Accommodation for Workers in Precarious Employment in Canada**

Karima Joy, *Dalla Lana School of Public Health, University of Toronto*

Death is a universal and natural part of existence. However, the current Canadian social context offers minimal space to honour bereavement as a part of the human condition. Although bereavement leave entitlements vary at the provincial level, under the Canada Labour Code, workers are federally entitled to 3 days of leave when an immediate family member dies, compelling some workers to suppress their grief and resume former levels of productivity. Prematurely returning to work may “stifle” some employees’ grief experiences, negatively impairing their well-being which can impact workplace productivity and costs. As previous efforts to conceptualize a bereavement care agenda have not considered precarious employment, I intend to address this gap in the literature by doing formative work that focuses on the intersection of bereavement and precarious employment for Canadian workers. The focus on workers in precarious employment is important because such workers are vulnerable to loss of employment, financial security, and/or the exacerbation of mental distress. For this study, I am using a multi-scalar approach combining critical qualitative research, feminist ethics, interviews, and policy analysis to generate knowledge on the everyday experiences of my selected population, accounting for social, economic, and political forces. Given the persistence of precarious employment, Canada’s aging population, and the impending death boom, generating multi-scalar knowledge on bereavement experiences in the context of precarious employment can aid in the development of bereavement legislation and public health strategies that reflect the experiences and needs of bereaved workers in Canada’s changing socioeconomic landscape.

### **Nursing Practice and Context: The Relationship Between the Hospital Setting and Environmentally Responsible Practice**

Maya Reshef Kalogirou, *University of Alberta*

Sherry Dahlke, *University of Alberta*

Sandra Davidson, *University of Calgary*

Climate change (CC) is an emerging challenge facing the global community. International research bodies have determined that CC is a considerable threat to human health, and healthcare



practitioners are being asked to reframe it as a major health concern. While nursing researchers are already developing the field of climate science within the profession, not enough is known about Canadian nurses. The purpose of this study is (a) to discover how Albertan nurses employed in a hospital understand CC and (b) to understand how the hospital's policies, physical spaces, and the social and cultural practices influence nurses' abilities to practice in an environmentally responsible (ER) manner. A focused ethnography is currently being conducted with nurses from four different hospital units. Preliminary analysis of the interview and observational data have identified that, while nurses understand CC at the macro-level and issues around waste management and resource conservation at their local level, they have difficulties linking the two. Although they identified resource waste as a major concern, participants were often uncertain of what could be done as the nature of their work required them to prioritize patient well-being over environmental impact. Despite prioritizing "green" activities at home (recycling, composting, home gardens, etc.), participants felt they were unable to bring these values into their work setting. Nursing is guided by a social mandate meant to improve the health of individuals and society, yet these findings indicate a schism between this mandate and the nursing practice occurring within the hospital. This poster will present preliminary data in more detail, and implications for future practice and study will be discussed.

### **"I Can't Help Sometimes and Judge": Nurses' Challenges in Caring for Mothers of Infants Withdrawing From Opioids**

Ira Kantrowitz-Gordon, *University of Washington*

Vania Rudolf, *Swedish Addiction Recovery Services*

Cynthia Price, *University of Washington*

The opioid epidemic has greatly increased the number of newborns exposed to opioids in utero and subsequently at risk for neonatal opioid withdrawal syndrome (NOWS). At-risk newborns require in-hospital monitoring for potential withdrawal symptoms including irritability, feeding difficulty, and poor sleep. Mothers with opioid use disorder (OUD) typically encounter challenges in early parenting related to feeling stigmatized for their substance use and guilt from their belief that they caused the newborn's suffering. The attitudes and beliefs of the nurses caring for these families can contribute to the positive or negative experiences of these families during this difficult transition. We surveyed nursing providers caring for newborns screened for NOWS in a large urban hospital in the Pacific Northwest, United States ( $n = 89$ ) on their caregiving experiences. Using qualitative description, we identified three themes in responses to questions about the personality characteristics of mothers with perinatal opioid use history and the challenges of caring for these families. The first theme, "bidirectional trust," highlighted the mutual distrust between mothers and nurses in caring for the infant. The second theme,

"mothers' unmet needs," highlighted how the mothers' unmet emotional, psychiatric, and pain control needs made their engagement in infant care difficult. The third theme, "social chaos," highlighted the challenges from limited social support and unstable housing. These findings underscore the need for educational tools to improve nurses' compassion for chemically dependent mothers and their infants. This may offer a practical approach to reducing stigma, developing a therapeutic relationship, and improving maternal and neonatal outcomes.

### **Crossroad Collaboration Insights of Fostering Patient Involvement and Facilitating Interprofessional Team Improvements**

Kelly Kilgour, *University of Ottawa*

This poster presentation introduces an active doctoral action research study conducted on two interprofessional teams in a Canadian hospital. Health organizations are keenly improving interprofessional collaboration (IPC) and patient involvement (PI)—with the goal of enhancing patient outcomes. IPC involves healthcare workers from different professional backgrounds working together to deliver more safe, effective, and comprehensive services; IPC is an important part of healthcare delivery. Another development is PI in health decisions, empowering patients and taking advantage of their care recipient insights; however, surveys mainly underpin this research. Qualitative research on PI and IPC is essential for quality patient care. Action research provides an active, systematic framework for inquiry while supporting collaboration between researcher and diverse stakeholders. Research objective is to collaborate with and facilitate learning among IPC medicine teams to improve patient and family caregiver involvement as well as relationship-centered care in their practices. Phase 1 of 30 patient and family caregiver interviews was completed over 4 weeks. Data analysis, guided by Miles, Huberman, and Saldaña, is proceeding with audio-recorded interviews, observational field notes, and researcher reflective notes. Thematic findings will be compared to recent patient surveys. Results will be summarised followed by researcher's strategies and insights of her current collaborations with IPC teams and patient advocate volunteers to improve PI in their practices (following study phases). This presentation may assist participants to gain a greater understanding of how to facilitate improvements in their IPC team practices, patient advocate partnerships, and PI integrations.

### **"Why Didn't You Put on a Uniform?" Reflections on Lessons Learned in Building Capacity for Qualitative Research in Malawi**

Mai-Lei Woo Kinshella, *Department of Obstetrics and Gynaecology, BC Children's and Women's Hospital; The University of British Columbia*

Leticia Chimwemwe Suwedi-Kapesa, *College of Medicine, IMCHA Project, Blantyre*

Alinane Linda Nyondo-Mipando, *College of Medicine, IMCHA Project/Department of Health Systems and Policy, School of Public Health and Family Medicine, University of Malawi College of Medicine*

Employing reflections on one's professional roles in relation to a setting where research is being conducted is one way of recognising researcher's position that is likely to affect validity of research findings. However, there is inadequate literature to provide lessons on reflections and conducting qualitative research in resource-constrained global health settings. This poster outlines the process in preparing for and conducting interviews and reflection on the lessons learned within the "Integrating neonatal health care package in Malawi" IMCHA project in order to build capacity for qualitative research in Malawi. I reflect about the use of health care workers as data collectors and my professional background as a nurse to conduct qualitative health research in Malawi within resource-constrained health settings. Data collected by health care workers in a health setting requires employing reflexivity by the interviewer to avoid taking things for granted that may be important for the study. Also, health workers interviewees often have heavy clinical responsibilities to fulfill, and dedication of their time to the study is compromised. We recommend that future studies should train data collectors to employ reflexivity to balance their professional roles as health care workers and their position as an interviewer. Researchers should plan for adequate data collection period to accommodate multiple roles that a health worker has to fill. Qualitative data collected in resource-constrained health settings will likely be compromised if time constraints are not considered.

### **Parents' Experience of Continuing a Pregnancy After the Diagnosis of a Fetal Life-Limiting Condition: A Qualitative Systematic Review**

Stephanie Lelond, *University of Manitoba; Winnipeg Regional Health Authority*

Roberta L. Woodgate, *University of Manitoba*

Susan McClement, *University of Manitoba*

Bruce Martin, *University of Manitoba; Winnipeg Regional Health Authority*

When expecting parents are told their baby's life is likely to be brief due to a fetal life-limiting condition (FLLC), they are faced with a heartbreaking choice to terminate or continue the pregnancy. While historically termination has been the assumptive choice, there has been a recent increase in parental desire for supports to continue these pregnancies, and healthcare providers face limited knowledge of parents'

experiences and needs. This qualitative systematic review will synthesize the best available evidence of parents' experiences of continuing a pregnancy after the diagnosis of a FLLC. Research questions include (1) What are parents' experiences from diagnosis to bereavement? (2) What conditions shape parents' experiences? and (3) What are parental needs when continuing a pregnancy after the diagnosis of a FLLC? Participants include any parent of a fetus that has been prenatally diagnosed with a FLLC expected to result in a natural perinatal death and has chosen to continue the pregnancy. Inclusion criteria are qualitative original research studies written in English, without date restrictions, published and unpublished papers in CINAHL, SCOPUS, JBI, PsycINFO, Cochrane, PubMed, and grey literature. Papers selected for full review are examined by two independent reviewers and assessed for methodological quality using the JBI critical appraisal tool. Data are extracted using the JBI Data Extraction Form, and findings are given a level of plausibility and synthesized using a meta-aggregative approach. This systematic review aims to advance healthcare provider knowledge to better support parents choosing to continue their pregnancy after the diagnosis of a FLLC.

### **First Nations on Reserve Early Cancer Detection: An Indigenous-Led Peer-to-Peer Qualitative Research Study**

Tamara Low Horn, *Pacer and Community Engagement Research Program, O'Brien Institute Cumming School of Medicine, University of Calgary*

Statistics show a rising cancer mortality rate in Indigenous, on-reserve populations in Alberta. This study was completed by two living on-reserve, Indigenous students in the Patient and Community Engagement Research (PaCER) programme to explore the experience in one Indigenous community with cancer diagnosis and accessible cancer screening. Working within Ownership, Control, Access and Possession (OCAP®) principals, we used the three-step PaCER framework holding a code-sign focus group with elders ( $n = 4$ ), conducting four narrative interviews and a member check ( $n = 2$ ). All data were analyzed iteratively, and time and appropriate cultural settings were provided to ensure participants' comfort, allowing depth and thickness of information and storytelling. Three main themes and five subthemes emerged: repercussions of residential school—(a) lost knowledge and (b) suffer in silence; gaps and barriers to early detection and diagnosis—(a) misdiagnosis/late Diagnosis, (b) transportation and housing, and (c) perceived attitude and treatment from medical staff; and gaining back knowledge and trust. All three main themes as well as the difficulties in connecting with traditional healing medicine and ceremony negatively impacted both early detection and timely and culturally appropriate treatment options. This is a small peer-to-peer qualitative study carried out in one Indigenous reserve. However, the results indicate a need for more experiential patient research within Indigenous communities to

understand the gaps and barriers to early detection. Given the negative experiences and lack of trust with the health provider system that we encountered, it would seem to be important that any research be undertaken by Indigenous researchers using a similar method of peer-to-peer research.

## **Resilience Among Christians and Muslims in Egypt and Canada**

Mary Makarious, *University of Toronto*

Douglas Bors, *University of Toronto*

Gerald Cupchik, *University of Toronto*

This study examined factors that shape the subjective experience of resilience in stressful situations for Egyptians of the Muslim and Christian faiths? What is more important: personal struggle, religious affiliation, or community support? The 201 Egyptian respondents included 112 females and 89 males (17–72 years old) with 132 living in Cairo (47 Muslims and 85 Coptic Christians) and 69 Coptic Christians in Toronto. Respondents described a stressful episode from their lives, and an index of “severity of the trauma” was derived. They also completed a 22-item “Coping with Life” questionnaire measuring (1) religious emphasis, (2) values and self-concept, (3) community involvement, and (4) a subjective assessment of resilience (“I am resilient/recovered from unexpected traumas”). Severity of trauma was not associated with a stronger feeling of resilience. Having values to promote equality, being made stronger by difficult experiences, learning valuable lessons from others, and having a healthy self-concept are the best predictors of subject resilience. Experiencing community and participating in the community is second in importance and general religious emphasis, rather than affiliation as either Muslim or Christian, plays a tertiary role. Also, Egyptians currently living in Cairo perceived themselves to be more resilient than those who moved to Canada, reflecting ongoing challenges. Successful personal struggle appears to play a central role in social adaptation.

## **Exploring the Lived Experience of Expert Nurses Entering a Master of Nursing Program: An Interpretive Phenomenological Analysis**

Lisa Mary-Quigley, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

In the literature, the transitional process of nurses returning to academia is often described as novice to expert. Expert nurses possess an enormous background of skill and experience, show strong analytical ability in novel situations, and are familiar with academic culture being baccalaureate prepared. An alternative, strength-based lens in which nursing expertise is retained and readapted by the expert nurse in the graduate academic environment is offered. The purpose of the author’s

proposed study is to explore the lived experiences of expert nurses entering a MN program using IPA. The model of expertise redevelopment will conceptually guide the author’s qualitative research question: What are the lived experiences of expert nurses entering into MN programs? Approval by the UM Research Ethics Board will be attained. Participants will include a small, purposeful, voluntary sample of three first-year MN students within the CoN with five or more years of active, practicing, registered nurse experience. The author will lead two, semi-structured interviews, followed by transcription, for each participant. Data analysis will include coding for thematic identification which will acknowledge both participant and researcher interpretation. Rigor will be strengthened using reflexivity, diarizing of perceptions, multiple interviews, member checking, memoing, triangulation of study sources, and regular discussions with the author’s graduate advisor. Information gleaned will advance existing knowledge of expertise redevelopment in academia, suggest strategies that encourage and support graduate flexibility in new and challenging academic environments, and assist nursing faculty to effectively support graduate students towards successful graduation in their MN programs.

## **Meaning of Conscience for Enrolled Nurses With Immigrant Background in Sweden**

Monir Mazaheri, *Department of Health Sciences, The Swedish Red Cross University College*

Eva Ericson-Lidman, *Department of Nursing, Umeå University*

Öhlén Joakim, *Sahlgrenska Academy Institute of Health and Care Sciences; Centre for Person-Centred Care, University of Gothenburg*

Astrid Norberg, *Ersta Sköndal Bräcke University College & Department of Nursing, Umeå University*

Conscience is an important concept in nursing and ethics, having various meanings in different cultures. In a multicultural society, people with different views on conscience have to cooperate, which demands understanding and respecting each other’s views while facing challenges. A growing number of healthcare professionals are of immigrant background, particularly within the care of older people. In Sweden, 18% of enrolled nurses and nursing assistants are foreign-born. Care for people with dementia who reside in residential care settings in Sweden is mainly provided by ENs. The care of people with dementia requires that care providers take many ethical positions. It is important to explore the meaning of conscience among care providers within different cultural contexts. Our study aimed to illuminate the meaning of conscience by enrolled nurses with an Iranian background working in residential care for Persian-speaking people with dementia. A phenomenological hermeneutical method guided the study. A

total of 10 enrolled nurses with Iranian background, aged 33–46 years, participated in the study. All worked full-time in residential care settings for Persian-speaking people with dementia in a large city, in Sweden. The study was approved by the Regional Ethical Review Board for ethical vetting of research involving humans. Participants were given verbal and written study information and assured that their participation was voluntary and confidential. Three themes were constructed including perception of conscience, clear conscience grounded in relations, and striving to keep a clear conscience. The conscience was perceived as an inner guide grounded in feelings, which is dynamic and subject to changes throughout life. Having a clear conscience meant being able to form a bond with others, to respect them, and to get their confirmation that one does well. To have a clear conscience demanded listening to the voice of the conscience. The enrolled nurses strived to keep their conscience clear by being generous in helping others, accomplishing daily tasks well and behaving nicely in the hope of being treated the same way one day. Cultural frameworks and the context of practice needed to be considered in interpreting the meaning of conscience and clear conscience.

### **Understanding Rehabilitation Student Experiences in Interprofessional Learning Environments**

Charlotte McCartan, *University of Alberta*

Sharla King, *University of Alberta*

Mary Roduta Roberts, *University of Alberta*

Individual learner levels, the complexity of tasks at hand, and diverse environmental contexts increase the challenge of interprofessional education (IPE) in health science programs. Due to the nature of IPE being variable and highly complex, there is a need to investigate individual learner experiences in specific programs to understand the full context of IPE in various practice settings (Cristancho et al., 2014). This interpretive inquiry utilizes complex learning theory to understand the summative IPE experiences of rehabilitation medicine (RM) students. Haji et al. (2013) stated that learning outcomes in the health sciences may result from multiple interactions in a complex fashion. This has changed the way educators think of learning from linear approaches to problems (that there must be one answer) to understanding the multiple, unpredicted solutions that may occur (Regehr, 2010). By understanding the interactions that create complexities, educational frameworks will be determined to help better prepare prelicensure students for the realities of practice. The design of this study will use an interpretive interview approach. Participants will be chosen through convenience sampling at the end of their programs. It is hoped that 12 semi-structured interviews will be conducted. Illustrations will be used alongside the interview and analyzed together. The findings of this study may serve to inform adaptable educational strategies regarding IPE in the practice setting and specifically within collaborative practices.

### **“I’ll Use It Differently Now”: A Youth Participatory Action Research Study Exploring Young Peoples’ Engagement With Networked Technologies**

Valerie Michaelson, *Brock University*

Valerie Steeves, *University of Ottawa*

**Background:** Many young Canadians experience high levels of connectivity through their use of social media and networked technologies. There is a growing body of literature that posits that such high levels of connectivity may have negative impacts on children’s physical, psychological, and social health. However, for the most part, research about young people and their use of social media and electronic screens is adult led. Arguably, the best people to provide insight into the relationship between young people and networked tech are the young people themselves. **Methods:** We used Youth Participatory Action Research (YPAR) methodology to codesign a project with six young people (ages 12–16) to evaluate their subjective experiences with both connection and disconnection to social media and networked technologies. The project was shaped around a media diary, which the youth researchers designed. They also set the parameters around their study; we would all keep this diary for 2 weeks and then choose a total of 7 consecutive days during the following 2-week period to not use social media or other networked technologies. We would use our media diaries to record our experiences throughout all 3 weeks. The study authors then interviewed the youth researchers about their experiences. This was intended to provide a space for individual reflection on the experience. These interviews were transcribed and then analyzed and interpreted by the entire group. **Results:** The overarching themes, complexities, and reflections that emerged throughout this study are reflected in the following quotations from the interviews: (1) “It wasn’t as bad as I thought it would be,” (2) “We don’t realize how much we use it,” (3) “It’s not as important as I thought,” (4) “There are benefits to disconnecting,” (5) “I would still rather have it,” and (6) “I’ll use it differently now.”

**Discussion:** The main benefit of the experience of intentional disconnection appeared to be having the opportunity to reflect on one’s own use of social media and other networked technologies and so to reconnect in a more thoughtful and intentional way. Young people’s experiences of social media and other networked technologies are complex, yet they are able to navigate this landscape with intelligent strategies and astute self-reflection. Throughout this enquiry, it became clear that their social media and other technologies were helping them to negotiate a complex world in helpful, fun, and meaningful ways but that sometimes a break was beneficial to many aspects of their health and well-being. Their self-directed exploration of disconnection in effect helped them to become reflexive practitioners who were able to revisit their social media and tech use with new understanding, insight, and control. Clearly, young people have a great deal of insights to

offer to contemporary discourse around the use of social media and other networked technologies. Their ideas would be beneficial for consideration by adult users as well.

### **The Role of Social Work in Supporting Individuals With Autism in Healthcare Settings**

Rae Morris, *School of Social Work, University of British Columbia*

Andrea Greenblatt, *Factor-Inwentash Faculty of Social Work, University of Toronto*

Individuals with autism face multiple barriers and inequities in relation to healthcare services and supports, and more research is needed on the potential role of allied health providers in enhancing access to equitable and effective care. The current presentation highlights the results of a qualitative research study exploring the experiences of medical social workers providing care to children with autism and their families. Fourteen social workers participated in semi-structured interviews that were audio recorded and analyzed for thematic content based on interpretive description methodology. Emerging themes were triangulated through team analysis and member checking. The current presentation focuses specifically one of the resulting themes highlighting some challenges and benefits of the role of pediatric hospital social work related to autism. Subthemes include (1) limited knowledge of relevant community resources, (2) lack of clarity regarding social work role related to autism, (3) promotion of family-centered care and family expertise, (4) promotion of resilience in families, (5) facilitation of communication, (6) advocacy, (7) service navigation, and (8) consultation with experts. The current presentation will situate the results of this study within the available research literature examining challenges and benefits to the role of social work with this population. Considerations and recommendations for how to effectively utilize and support social workers in interprofessional teams will be shared. We propose that these findings can help guide future healthcare service research and policy aimed at enhancing service provision and quality of care for individuals with autism and their families seeking healthcare services.

### **“So You’re a Tough Guy, Eh?”: Constructions of Identities by Competitive Male Ice Hockey Players**

Kirsten Morrison, *Laurentian University*

Throughout sport psychology literature, the relationship between identity and sport has been explored; however, research on how athletes come to develop certain identities has been lacking, particularly in aggressive sports, such as hockey. The proposed study will explore how competitive

male ice hockey players construct their identities through sport participation. Framed within a social constructionist paradigm, and guided by narrative theory, this study addresses the intersectionality of multiple identities such as masculinity, race, and social class. Participants will include six-to-eight players from three competitive hockey teams in Sudbury, Ontario, Canada. Unstructured, conversational interviews will take place with each participant, asking them questions pertaining to their experiences in sport, with injury, and as a hockey player. Interpretative thematic analysis will be completed to identify common themes as well as differences between the narratives. In line with narrative theory, keeping the integrity of the participants’ stories will be the focus of data analysis. Based on previous literature, anticipated findings include identities of athletes being shaped by their early sporting experiences, the culture of sport, and idealized masculine values. The goal of the proposed study is to provide insight into the way sociocultural processes are used for forming identities while also leading a path of new research into identity formation and the impact of sport culture. The results of this study will be important for facilitating a better understanding of how athlete identities are shaped both negatively and positively and their implications for individuals both in and out of sport.

### **Parents’ Experiences When Caring for a Child With Post-Concussion Syndrome: A Proposed Qualitative Study**

Kealy Murray *University of Manitoba*

Donna Martin, *University of Manitoba*

Lynn Scruby, *University of Manitoba*

Concussion or potential brain injuries contribute to 80% of children’s emergency department visits. One in four Canadians identified that they do not know how to manage a concussion, thus leading to an increased risk for post-concussion syndrome (PCS). PCS is defined as concussive symptoms that last beyond 4 weeks. The purpose of this proposed study is to explore parents’ experiences caring for a school-aged child with PCS. The research question is “What are parents’ experiences caring for a school-aged child with PCS?” A qualitative descriptive design will be used with a purposive sampling technique. Following ethical review board approval, participants will be recruited from a clinic setting in a Western Canadian city that is specific to pediatric concussion management. One-hour, semi-structured, face-to-face interviews will be conducted with 10–15 legal guardians or parents of a school-aged child diagnosed with PCS. Digital recorded interviews will be transcribed verbatim. Field notes and a reflective journal will be documented ensuring data triangulation. Coding of several transcripts and field notes will be independently conducted by all researchers. All researchers will meet to compare and contrast the preliminary codes, categories, and themes to add rigor to the data analysis process. By gaining a deeper

understanding of parents' experiences caring for a school-aged child with a concussion and PCS, health care providers may develop targeted and relevant educational tools, resources, and support for parents caring for a school-aged child with a concussion and PCS.

### **Unveiling the Service Delivery Landscape for Individuals With Neurodevelopmental Disabilities: Parents' Experiences of Service Navigation Within Urban and Rural Areas in Alberta**

David B. Nicholas, *University of Calgary*

Roslynn Zulla, *University of Alberta*

Wendy Mitchell, *University of Calgary*

Across their developmental trajectory, children with neurodevelopmental disabilities (NDD) will have multiple needs and thus require finding services from a variety of different sectors. In this mixed methods study, survey as well as individual and group interview data were collected from 17 youth with DD and 93 parents. Findings demonstrate that the search for services across health, education, disability, and the social care sectors is fraught with multiple gaps. Parents describe the service delivery landscape as a "maze" comprised of "multiple hoops" that involve lengthy paperwork, engaging with multiple people, enduring long waiting times for services, and tirelessly advocating for services that the child with NDD is qualified for and needs. This landscape is further complicated with frequent changes in program and funding eligibility, and parental gaps in awareness of services, and a lack of knowledgeable service providers regarding service access pathways. This has resulted in parents feeling "burnt out" and distrustful of services and parental worry about whether or not services will be available for their child in the future. To buffer these stressful experiences, parents have relied extensively on their personal skills/resourcefulness (e.g., being proactive), and their social networks accrued throughout their journey of navigating services. Implications of these findings suggest that facilitating the experience of searching for services for parents must move beyond individual capacity-building initiatives. Systemic processes need to be developed, with continual updating to ensure ongoing and equitable access. These findings and implications will be presented with recommendations for moving forward.

### **Stakeholder Engagement in Digital Health: Codesigning an Online Resource for People Who Experience Painful Sex**

Heather Noga, *Women's Health Research Institute*

A. Fuchsia Howard, *University of British Columbia*

Kiran Parmar, *University of British Columbia*

Paul Yong, *University of British Columbia*

Endometriosis is a gynaecological disease that affects 1 in 10 Canadian women and can lead to painful periods, chronic pelvic pain, and painful sex. Despite its devastating effect on sexual functioning and interpersonal relationships, there is limited accessible, evidence-based information to help people understand their symptoms, seek appropriate care, and make treatment decisions. As the knowledge translation component of a wider project, we originally set out to create an online resource to convey information about somatic mutations in endometriosis. However, our initial focus groups identified the need for an online space that could provide general information about painful sex and convey hope, destigmatization, empowerment, and connectedness in a visually appealing way. A review of the readability and quality of existing online resources revealed a lack of friendly, accurate, and visually appealing plain language content. Guided by patient-oriented research, integrated knowledge translation, and agile development, we aimed to identify and engage a diverse group of stakeholders including clinicians, patients, researchers, endometriosis organizations, health administrators, and website developers in the creation of an online platform for people with endometriosis-related sexual pain. The result was an appealing, informative website for a diverse audience achieved through iterative, collaborative decision making. All contents were conveyed through short plain language messages, visual images, and design. As an ever-evolving process, the next steps will include usability testing and qualitative interviews to explore user experience and identify gaps in information needs with the ultimate goal of better health outcomes for people with endometriosis and painful sex.

### **The Nature of Alcohol Consumption Messages in Korean Dramas**

Rubini Pasupathy, *Texas Tech University Health Sciences Center*

Jaesook Gho, *Liberty University*

Brittany Duhart, *Texas Tech University Health Sciences Center*

South Korea has one of the highest rates of alcohol consumption and alcohol-related problems in the world. There has been a global rise of the popularity of South Korean media extending beyond Asian countries to countries in the Middle East and North and South America. In the United States, there is a devoted community of K-drama fans that are primarily not of Korean or Asian origins. These K-drama fans actively embrace South Korean culture including the food, fashion, and language. Alcohol is widely advertised and portrayed across the South Korean media. The consumption of alcohol has a strong social meaning within the South Korean culture. K-dramas

promote South Korean culture including cultural norms regarding alcohol consumption. Social learning theory posits that behavior is learned through observational learning, and cultivation theory suggests that prolonged exposure to specific messages in the media shapes viewers' perception of reality. The purpose of this embedded mixed methods study is to explore the nature of the portrayal of alcohol consumption in K-dramas and identify the prevalent messages about alcohol consumption and related alcohol behaviors. A mixed methods design was used to conduct a content analysis on popular K-dramas. Results indicate that alcohol consumption is frequently portrayed, specifically as a coping mechanism and the negative consequences of intoxication are rarely addressed. It is important to address the normalization of the South Korean drinking culture as alcohol consumption is a leading risk factor of the global disease burden.

### **Facilitators and Obstacles Influencing the Adoption of Interventions for Chagas Disease Prevention**

Elizabeth Pellecer Rivera, *The University of Maine; Universidad del Valle de Guatemala*

Sandra De Urioste-Stone, *The University of Maine; Universidad del Valle de Guatemala*

Pamela Pennington, *Universidad del Valle de Guatemala*

Teresa Aguilar, *Universidad del Valle de Guatemala*

Chagas disease is a neglected vector-borne disease that represents a major challenge to several Latin American public health systems as it affects communities in rural environments. In Guatemala, a national program focused on controlling the vector through insecticides was launched in 2001. Given that its transmission is complex, being influenced by socio-cultural, economic, and political factors, focusing solely on vector control through chemical strategies has not been effective or sustainable. Between 2009 and 2014, we implemented a community-based intervention in a municipality in the eastern region of Guatemala where Chagas disease was endemic. Our goal was to improve Chagas disease prevention and control by tackling ecological, biological, and social risk factors. In our mixed methods study, we aimed to understanding risk factors associated with Chagas disease, to identify enablers and barriers to adoption of our community intervention, and to gain insights into elements of sustainability of community-based interventions. We conducted a series of semi-structured interviews in nine intervention communities with a total of (add number here) individuals and distributed postintervention surveys in nine intervention and nine control communities. Constructs from the diffusion of innovations theory were utilized as an analytic framework. (Add a brief summary of results here.) In this presentation, we will discuss our results in more detail, with a focus on how they can help

inform ongoing interventions and control programs in rural settings.

### **Assessing Media Content on Travel and Mosquito-Borne Disease Dynamics**

Elizabeth Pellecer Rivera, *The University of Maine*

Sandra De Urioste-Stone, *The University of Maine*

Morelys Rodriguez Alfonso, *University of Puerto Rico at Cayey*

During the last decade in the Americas, we have been confronted with two emerging mosquito-borne diseases, chikungunya and Zika, that have presented challenges across the region given multiple outbreaks since 2013 and 2015, respectively. The introduction of these two diseases in recent years demonstrates the role that the interconnectedness of today's globalized world poses for global health. Studies have shown that international trade and travel activities are major drivers of the spread of these and other diseases from endemic regions to new places around the globe. The aim of this study is to understand how the media in selected destinations in the Americas present information on new mosquito-borne diseases as they relate to travel. To achieve this, we will conduct a content analysis to evaluate the messages presented in newspapers, travel guides, government, and travel agencies regarding tourism and Zika and chikungunya, specifically for United States, Guatemala, and Puerto Rico. We are using Nexis Uni, Global Newsstream, and EBSCO Host to conduct the newspaper searches. More than 2,000 newspaper articles have been identified, with the majority having been published in 2016. Information gathered through the content analysis will aid in helping interpret how the media likely influences travelers' risk perceptions, behavioral intent, and actual travel behavior. Further, we expect that the information gathered will inform public health and tourism messaging and management strategies in the United States, Guatemala, and Puerto Rico.

### **Developing and Testing a Community-Based Nursing Intervention to Improve Engagement of HIV Patients in Care and Treatment (Conect)**

Hilary Piercy, *Sheffield Hallam University*

Charlie Hughes, *Sheffield Teaching Hospitals NHS Foundation Trust*

Julia Greig, *Sheffield Teaching Hospitals NHS Foundation Trust*

The health outcomes now achievable for people living with HIV require long-term engagement with treatment and care. This is problematic for a significant minority. Disengagement from HIV services is strongly associated with poor health

outcomes and reduced life expectancy. It accounts for a large proportion of avoidable hospital admissions and has considerable public health implications associated with onward transmission. Preventing disengagement is a major challenge for HIV services. Those who disengage from care commonly have complex needs and a range of psychosocial problems. This indicates the need for reengagement interventions that take an individualised approach. The aim of this project is to develop and test a community-delivered nursing intervention designed to prevent individuals disengaging from HIV treatment and care. The project involves development of a reengagement intervention and delivery of the intervention through a pilot community HIV nursing service. The intervention is structured around a strengths-based approach and theoretically based on the Behaviour Change Wheel. A process and outcome evaluation will establish effectiveness and acceptability of the intervention. A structured and theoretically informed intervention has the potential to make a significant contribution to reducing disengagement rates in this population. Establishing a pilot service to deliver this intervention and conducting a comprehensive evaluation will enable us to assess its effectiveness and identify the key determinants of success to inform transferability of this approach.

### **Therapeutic Itinerary According to “Reasons for” and “Reasons Why” of Users With Malignant Neoplasms in Regions of the State of São Paulo (Brazil)**

Regina Popim, *University Paulista—UNESP*

Karina Freitas, *University Paulista—UNESP*

Mariela Lombardo, *University Paulista—UNESP*

Cancer is considered a public health problem, and its diagnosis and treatment are paramount for patient survival. The objective of this study was to understand the experiences of users with malignant neoplasias who arrived at the cancer center, according to the route taken in the search for treatment. This is a qualitative research with a phenomenological approach by Alfred Schutz. Data were collected through a semi-structured interview, with 26 users with malignant neoplasms and analyzed with the help of Nvivo software. Based on the approach used, this study made it possible to understand the social reality of users with cancer in the use of the Brazilian Unified Health System (SUS) in their move between their “reasons for” and “reasons why”: They seek access to treatment (public–private) supported by family relationships that help them in care decisions because there is disbelief in basic health care and lack of places to the specialized service. Although cancer is a public health problem, the way the health care network is prepared does not include the user’s rapid access to the health system. The study revealed the weaknesses of SUS in the care network for patients with malignant neoplasia. And the reference of Alfred Schutz can contribute to the reflection on the national health policy and can bring improvement to the network of

attention to the patient with malignant neoplasia, aiming to make it faster and more effective.

### **Examining The Role of Mental Health Disorders on Adult Functioning Among Emerging Adults With a History of Out-of-Home Care (PhD Dissertation Proposal)**

Javiera Pumarino, *University of British Columbia*

Approximately 40,000 Canadian children and adolescents live in foster care and thousands age out of care between ages 16 and 19 each year. There is growing concern over the vulnerability of these youth, partly because of numerous highly publicized reports of premature death related to untreated mental health and substance use issues. The objective of this study is to investigate the role of mental health disorders on adult functioning among Canadian emerging adults with a history of foster care. This study will use an explanatory mixed methods approach, which will involve a quantitative stage followed by a qualitative stage to explore the quantitative findings in more depth. The qualitative stage will examine the complex relationship between the foster care experience, mental health disorders, and the transition into adulthood. It will explore the experiences of a group of emerging adults (between 18 and 29 years) with a history of foster care and a diagnosed mental health disorder. The study will be implemented in partnership with an intensive case management program based in Vancouver, British Columbia. Through an integrated knowledge translation process, program stakeholders will be involved in the planning of all steps of the study, including definition of specific research questions, which will be informed by the quantitative findings and methodological decisions (e.g., data collection approach and tools). Evidence generated from this study will increase our understanding of the psychosocial needs of youth transitioning out of care and will inform the development of interventions to support their successful transition into independent adult living.

### **Being Part of a Team—Healthcare Personnel Experiences of Supporting Youth With Diabetes Type 1**

Malin Rising Holmström, *Mid Sweden University*

Marie Häggström, *Department of Nursing Sciences, Mid Sweden University*

Siv Söderberg, *Department of Nursing Sciences, Mid Sweden University*

Type 1 diabetes (T1D) is a common childhood disease worldwide, and Sweden has the highest incidence next to Finland in the world (900/y). Furthermore, 7–8,000 children and adolescents live with T1D with ongoing treatment. Health-care personnel play an important role at the onset of the illness and also through the often-long period of frequent contact between the



youth and healthcare during the upbringing years learning to manage the illness. The aim was to describe health care personnel's experience of supporting youth with T1D in daily life and school. A qualitative research design was used, and interviews were performed with seven health care personnel: pediatric physicians, pediatric nurses (ward and clinic), dietician, psychologist, social counselor, and school teacher (hospital school). The interviews were subjected to qualitative thematic content analysis. The preliminary analysis identified three themes: need for a flexible organization, imbalance in support needs and resources, and support from teamwork. A preliminary conclusion could indicate that healthcare for youth with T1D needs to be more flexible and accessible. Furthermore, there is an imbalance between support needs and health care resources, and this requires new ways of working to provide care to youth. The healthcare personnel experience the teamwork positively and has created cross-professional perspectives, strengthened competence, increased understanding, and knowledge for youth with T1D's daily life and school situation.

### **Supporting Youth With Diabetes Type 1—Experiences From Parents and Healthcare Personnel**

Malin Rising Holmström, *Mid Sweden University*

Marie Häggström, *Department of Nursing Sciences, Mid Sweden University*

Siv Söderberg, *Department of Nursing Sciences, Mid Sweden University*

Type 1 diabetes (T1D) is a common childhood disease worldwide, and Sweden has the highest incidence next to Finland in the world (900/y). Furthermore, 7–8,000 children and adolescents live with T1D with ongoing treatment, and parents often find it stressful to give optimum support to their children. Health care personnel play an important role in the collaboration with the family at the onset of the illness and also through the often-long period of frequent contact during the upbringing years learning to manage the illness. The aim was to describe parents and health care personnel's experience of supporting youth with T1D in daily life and school. A qualitative research design was used, and interviews were performed with 13 parents (10 mothers and 3 fathers) and 7 health care personnel from a pediatric hospital and clinic. The interviews were subjected to qualitative thematic content analysis. The preliminary analysis identified four themes: need for flexible and accessible support, imbalance in needs and resources, obstacles and possibilities collaborating with school, and support from teamwork. A preliminary conclusion indicates that tomorrow's healthcare needs to be more flexible and accessible. There is an imbalance between parents' support needs and health care resources, and collaboration with school needs to be improved. Working in a team supported healthcare personnel and parent's

competence regarding youth with T1D's daily life and school situation.

### **Perspectives of Patients With Chronic Pain About a Pain Education Video**

Lisa A. Royse, *University of Missouri*

Erin A. Dannecker, *University of Missouri*

Daniel Vilceanu, *University of Missouri*

Melissa D. Warne-Griggs, *University of Missouri*

Approximately 20% of U.S. adults have chronic pain. Patient education can decrease patients' pain. An educational approach focused on the psychosocial factors that influence pain called "Explaining Pain" (EP) has gained prominence. However, patients' responses to the EP approach have varied. This study focused on participants' responses to video delivery of the EP approach. Guided by an interpretivist, phenomenological approach—to strive to make sense and understand the world through subjective descriptions of individuals' lived experiences—we conducted 15 semi-structured interviews with adults who have chronic pain. During the interview, participants (1) described their pain, (2) watched a 6-min online video that included the EP educational approach, and (3) answered questions about their perceptions of the video and changes in beliefs about their pain. Two members of the research team conducted a content analysis of all transcripts. Six broad categories emerged from the data: (1) importance of understanding the causes of pain, (2) opinions about the video's quality, (3) participants' agreement with the video, (4) participants' disagreement with the video, (5) video's educational value, and (6) recommendations for the videos use and improvement. Study results support that the video may be a clinically feasible medium for delivering patient education about pain and may facilitate patient-provider discussion. Participants perceived the EP content as both validating and invalidating, and their beliefs about pain changed in variable ways. Variable responses may have resulted from participants' need for validation that their pain is real and their perceptions that the EP content was personally relevant.

### **Patient Experience of Living With a Cardiac Arrhythmia**

Tigana Runte, *University of Lethbridge*

Shannon Jarvie, *University of Lethbridge*

Mary Runte, *University of Lethbridge*

The overarching goal of this study, funded by the Cardiac Arrhythmia Network of Canada, is to capture patient experiences compiling a map (or compilation of maps) of the arrhythmia patients' journey and identifying points of crisis or struggle as they relate to the social, psychological, financial, and employment effects of having an arrhythmia condition. Focus

groups ( $n = 10$ ) engaged patients ( $n = 57$ ) and caregivers ( $n = 10$ ) in a mapping exercise whereby they constructed individual maps of their path from the emergence of symptoms to the present time. Focus group discussion allowed patients to embed personal narratives onto the maps to relay illustrative experiences of their journeys. These maps and narratives were then analyzed for common themes, and cocreated maps were created with patient partners, who also coled the focus groups, which were then shared with participants for their feedback. Patients face considerable challenge as they negotiate their way from the emergence of symptoms, through diagnosis, and into and beyond treatment. Female patients, for example, report considerable emotional struggle as they struggle to have their symptoms addressed by care providers finding diagnosis to be a relief (albeit temporary) from ambiguity. Male patients experience more uncertainty and identity challenges regarding employment issues. Patients with life-threatening genetic arrhythmia (or surviving family) face social barriers as well as significant emotional challenge. The financial implications, from hospital parking costs to insurability to employment risk, are of a significant concern to patients. The study will cumulate in a patient-focused and patient coled priority setting exercise, examining future research and practice within the network.

### **“I’d Cry if It Went Away.” Interviews with Clinicians and Pharmacists About Referral to and Use of a Pharmacy-Led Opioid Tapering Program**

Jennifer Schneider, *Kaiser Permanente Center for Health Research*

Alison J. Firemark, *Kaiser Permanente Center for Health Research*

Dea Papajorgji-Taylor, *Kaiser Permanente Center for Health Research*

To address the growing opioid crisis, Kaiser Permanente Northwest (KPNW) implemented a pharmacist-led program to support patients tapering off opioid medications. Through interviews with the program staff (pharmacists) and primary care providers (PCPs), we explored barriers and facilitators for referring patients to this resource. In-depth guides were developed, and interviews were conducted by phone or in person. Interviews were audio-recorded, transcribed, and coded using NVIVO software. Content analysis resulted in identifying key themes on reasons why PCPs refer or not to the tapering program. Thirty-five interviews were completed: 15 pharmacists/staff and 20 PCPs. Analysis revealed complex pain patients on high doses of opioids who require more attention than the PCPs can offer are likely to be referred to the program. Pharmacists observed PCPs more often refer when they have a large number of assigned patients requiring a taper. Barriers to PCP referral and use of the program included patient preference for PCP to manage the taper; forgetfulness of the resource; and competing

organizational demands. Pharmacists observed that PCPs less likely to refer are comfortable managing opioid tapers on their own. PCPs cited lack of direct access to a program pharmacist in their clinic for consultation as a barrier to use. Our initial interview findings demonstrate under what circumstances PCPs are likely to refer patients to the opioid tapering program and identify several areas that could improve referrals to the service, including increased program presence in clinics and reminders to PCPs about the nature and scope of the tapering program.

### **Nurse-to-Nurse Communication What Is It and What Is It Good For? A Mixed Method Study to Examine Communication Between Nurses, Utilizing Qualitative Phenomenology to Elicit the Day-to-Day Experiences of Communication Between Nurses on an Acute Care Unit**

Catherine Schoales, *Lakehead University*

Mirella Stroink, *Lakehead University*

The ratio of registered nurses (RNs) to patients in Ontario is 669 per 100,000 people as compared to the rest of Canada at 828 RNs per 100,000 people. How has this shortage of RNs affected the practices of nurses? We have seen an increase in RN turnover, absenteeism, and intent to leave the profession. Nurses' ability to communicate with each other directly affects the outcomes of patients they care for and the collaborative practices on the unit, but to date, we know very little about the nurse-to-nurse communication from the perspective of the nurses and how it affects their professional practice. Utilizing complex adaptive systems theory as a framework would give us insight into the movement of information within a system and the connection to the emergent behaviours we see within the system. Qualitative phenomenology would allow the nurses to voice their perception of their day-to-day lived experiences of what communication is to them, how they communicate, and how communication affects their practice. This study proposes the use of qualitative phenomenology combined with the quantitative methods of social network analysis to visualize networks and network structures between nurses on the unit and surveys to measure organizational commitment, trust, and citizenship behaviour. SNA allows the nurses the ability to visualize the network they communicate within while their perception of communication would contribute to a deeper understanding of the network and emergent behaviours that are seen on the unit in which they work.

### **“I’m Finally Home”: Refugee and Refugee Health Care Provider’s Voices Inform Survey Tool Development**

Lynn Scruby, *Rady Faculty of Health Sciences, College of Nursing, University of Manitoba*

**Silvia Alessi-Severini, Rady Faculty of Health Sciences, College of Pharmacy, University of Manitoba**

**Moni Fricke, Rady Faculty of Health Sciences, College of Rehabilitation Sciences, University of Manitoba**

Refugee health care is a growing concern in Canada with the recent influx of arrivals and the complex nature of policies and funding structures. Analysis from qualitative interviews and a quantitative survey will provide insights into better understanding of the educational and service needs of refugees and their care providers. A mixed methods approach using a sequential exploratory research design was initiated, whereby an initial qualitative descriptive phase of the study was carried out to subsequently inform the development of a survey in the quantitative phase. Semi-structured interviews were held with 11 healthcare providers from different professions and nine newcomers to Manitoba. Providers included two physicians, three nurse practitioners, two physiotherapists, two pharmacists, one social worker, and one occupational therapist. Interview transcripts were thematically analyzed for overarching themes by the authors. The resulting themes included issues around accessing appropriate health services, funding challenges, cross-cultural manifestations of illness and wellness, and role clarification of the health team members. Thematic analysis contributed to question determination in the development of a survey tool with a research design to distribute to members of the professional associations of nursing, pharmacy, physiotherapy, and medicine. This interprofessional approach will ultimately translate into a framework for health care delivery to refugees which can be applied in further research. Interprofessional collaborative approaches are essential for improving population health, health systems, and health outcomes.

### **Meanings of Patient Participation in Hospital Care as Narrated by Orthopedic Nurses**

**Cecilia Segevall, Department of Nursing Science, Mid Sweden University**

**Kerstin Björkman-Randström, Department of Nursing Science, Mid Sweden University**

**Siv Söderberg, Department of Nursing Science, Mid Sweden University**

The study will provide a deeper understanding of meanings of patient participation for older people recovering after hip fracture surgery from the perspectives of orthopedic nurses. Patient participation in care has been discussed in nursing research for several decades due to that the role of the patient has changed to being more involved in care. A hip fracture due to a fall is one of the most severe health issues that affects older people which often leads to dependence on family and friends due to physical impairment. Patient participation may enhance quality of care and patient satisfaction and strengthen the older people recovering from hip fracture surgery's ability to manage at home after

discharge from hospital. However, several challenges still surround achieving participation. Thus, this study aims to elucidate meanings of patient participation in hospital care from the perspectives of nurses working at an orthopedic unit. A phenomenological hermeneutic method inspired by the French philosopher Ricoeur will be used to interpret meanings of patient participation from the orthopedic nurses' perspective with focus on older people recovering hip fracture surgery. A purposive sample of 10–12 nurses who have been working in an orthopedic unit for more than 6 months will be interviewed with a narrative approach. The phenomenological hermeneutic interpretation consists of three phases, naïve understanding, structural analysis, and comprehensive understanding and reflection. The findings will be presented in themes and subthemes. Preliminary findings will be presented at the conference.

### **Disclosure Experiences in Male Childhood Sexual Abuse**

**Asaly Skrenes, University of Edinburgh**

Childhood sexual abuse (CSA) is a common and harmful problem that has potentially long-term repercussions for its victims. Many negative CSA outcomes may be compounded by nondisclosure or a delay in the disclosure of the abuse, both of which are more common among male survivors. Of the relatively few studies on men, findings suggest that lower disclosure rates in these survivors, as compared to their female counterparts, may be due to pressures to conform to traditional masculine norms, fear of being viewed as homosexual, refusal to label the experience as abusive, and a lack of supportive resources. Using constructivist grounded theory, the aims of this study are to (a) investigate what contributes to men delaying or underreporting their experiences of CSA, (b) explore how these and other factors play a role in the positive or negative CSA disclosure experiences of these men, and (c) understand how disclosure experiences help or hinder men's healing process following CSA.

Constructivist grounded theory, outlined by Kathy Charmaz, is beneficial for research in complex situations in which theory is sparse or underdeveloped. This methodology recognizes that reality is an interactive process influenced by cultural, temporal, and structural contexts, where the participants and the researcher together co-construct a theory. Unlike other traditional forms of grounded theory, constructivist grounded theory accounts for multiple meanings derived from the data and emphasises retaining the voice of the participants. This is particularly appropriate for this area of research, given the relative invisibility of the voices of male CSA survivors within the literature.

### **Patients' Perspectives of BETTER WISE, a Cancer and Chronic Disease Prevention and Screening Project**

**Nicolette Sopcak, University of Alberta**

**Maryam Kebbe, University of Alberta**

**Carolina Aguilar, University of Alberta**

**Donna Manca, University of Alberta**

BETTER WISE is a cancer and chronic disease prevention and screening (CCDPS) program to improve CCDPS for cardiovascular disease, diabetes, cancer, and associated lifestyle factors in patients aged 40 to 65. Thirteen primary care team members (e.g., nurses, dietitians) were trained as a “prevention practitioner” (PP) to meet with patients for a 60-min visit to discuss patients’ individual risk for chronic diseases and associated personal lifestyles factors such as smoking, alcohol, physical activity, and diet. Employing principles of brief action planning (BAP) and shared decision making (SDM), PPs develop a “prevention prescription” with patients to guide next steps (e.g. completing eligible screenings, lifestyle goals).

To better understand patients’ perspectives in the context of CCDPS, we analysed 270 patient-written feedback forms using latent content analysis (e.g., what they liked about the visit, what they would like to be different). Four themes emerged: (1) likeability of the visit (tone of visit, individualized care), (2) utility of the visit (discussing personal factors, SMART goal setting), (3) quality and role of the PP (interpersonal skills, evidence-based approaches), and (4) further recommendations (establishing public health promotion efforts). Additionally, patients and PPs both completed a quantitative assessment to measure SDM using the Alberta Shared decision maKing Measurement Instrument (ASK-MI) tool. ASK-MI indicated that patients’ preferences and abilities were correctly identified by PPs and used to jointly make health-related plans. Our findings suggest that patient-centred communication and effective SDM are important to help patients understand their personal risks and to develop meaningful health-related goals.

### **Young People’s Experiences Living With Home Mechanical Ventilation: A Critical Narrative Inquiry Study**

**Elizabeth Straus, University of British Columbia**

The numbers of young people (ages 16–40) living with home mechanical ventilation (HMV) are increasing, and research about their experiences is emerging. Yet, what it means to live well for these young people has received little attention despite the centrality of the concept of quality of life in HMV research and practice. In existing studies with young people living with HMV, analyses of the complex interplay of experiences and social contexts are also limited. This presentation will articulate a theoretical framework and design for a study aiming to better understand “living well” for young people living with HMV through exploring their everyday experiences. A relational and critical theoretical framework to guide the study will be presented that illustrates how social structures and conditions, assumptions, and discourses are shaping and are shaped by young people’s experiences. An overview of the critical narrative inquiry methodology for this study that will recruit young people living with HMV from one Canadian province

and one U.S. state will be presented. Methods for generation of field texts—coming alongside young people in their daily lives and the generation and sharing of stories through photographs to reflect participants’ lives, daily struggles, and meaningful experiences—will also be described. The anticipated complexities and challenges in study design with this population will also be discussed. The findings of the study may be used to inform programs and policy for young people living with HMV and could challenge assumptions concerning quality of life and living well for this population.

### **What’s Your Migration Story? Commonalities and Differences Between Cross-National and Internal Migrants of Chinese Origin**

**Dan Tao, Concordia University**

**Sijia Li, China Academy of Sciences**

**Xiaopeng Ren, China Academy of Sciences**

**Andrew G. Ryder, Concordia University; Jewish General Hospital**

Both cross-national migrants (CM) and internal migrants (IM) undergo an acculturation process, which can be a stressful experience. Interviews were conducted in Mandarin to compare the migration stories of CMs in Montreal ( $N = 20$ ) and IMs in Beijing ( $N = 10$ ). Thematic analysis was used, and themes were grouped under the acculturation framework. Under sociocultural conditions, respondents from both groups experienced a high level of distress due to adjustment challenges and discrimination, with IMs facing more severe discrimination and more prolonged life pressure. Under orientations towards mainstream and heritage cultures, both groups found it hard to be close friends with locals and noticed increased distance from people from hometowns. Finally, under well-being outcomes, both groups exhibited personal growth and a mixture of positive and negative feelings throughout the journey. CMs embraced a fusion cultural identity over time, whereas IMs developed more resilience but less sense of belonging to the mainstream society.

### **The Role of Family in Help-Seeking Delays in Young Adults With Depressive Disorders in Singapore**

**Wen Lin Teh, Institute of Mental Health**

**Laxman Cetty, Institute of Mental Health**

**Ellaisha Samari, Institute of Mental Health**

**Shazana Shahwan, Institute of Mental Health**

Family is a crucial support system where mental health issues of young adults may be first expressed; help-seeking

behaviours are therefore contingent on familial support. From existing research on stigma, families can impede help-seeking efforts by keeping mental illness hidden out of fear of negative social consequences. Specifically, we wanted to find out how familial attitudes of mental illness could influence help-seeking efforts of young adult individuals. Face-to-face semi-structured interviews were conducted among Chinese, Malay, and Indian young adult outpatients, aged 20 to 35 years with depressive disorders, recruited from a tertiary psychiatric hospital in Singapore. Participants narrated their histories of depression and their families' thoughts of them getting diagnosed. The study reached data saturation after 10–12 interviews per ethnic group (total of 33 interviews). Transcripts were analyzed thematically using the Nvivo software. Codes were derived and analyzed iteratively through multiple discussions between five coders, after which a high inter-rater agreement of 0.73 (kappa) was achieved. Three themes emerged: (1) trivializing (i.e., overexaggerated response to stress, choosing to be sad, reasons for depression not justified), (2) stigmatizing attitudes (i.e., stereotypes, excuse for bad character), and (3) delays in help-seeking and a lack of support (i.e., inaction/denial/lack of understanding, ill advice addressing the inherent lack of coping or flawed character, distrusting psychiatric treatment). We did not find consistent ethnic differences in these themes. Our results indicate a need to align illness perceptions between the family and the individual with depression and address barriers in help-seeking for mental illness.

### **Living in the Shadows: A Qualitative Exploration of Parents' Experiences Caring for a Child With Functional Constipation**

Alison Thompson, *University of Alberta*

Shannon MacDonald, *University of Alberta*

Eytan Wine, *Division of Pediatric Gastroenterology & Nutrition, Faculty of Medicine & Dentistry, University of Alberta*

Shannon Scott, *Faculty of Nursing, University of Alberta*

Functional constipation (FC) is the most common pediatric digestive complaint; upwards of 20% of Canadian children suffer from this condition. FC is associated with profound physical, psychosocial, emotional, and financial burdens for families. Parents are key stakeholders tasked with implementing, monitoring, and titrating treatments that may be required for months or years. Despite the importance of parents' role, there is little research examining about how families live with pediatric FC. Consequently, there is no clear understanding of what resources and information parents need to feel successful caring for a child with FC. The purpose of this research is to explore parents' experiences related to caring for a child with FC. We used Interpretive Description methodology, reflecting our intention to produce clinically relevant and usable knowledge. Parents of children with FC were recruited through

advertising in community locations and online forums. Potential participants self-identified themselves to the researcher via phone or email contact. We conducted 14 semi-structured interviews in person or online. Data collection and analysis occurred concurrently, with analytic scaffolding from research literature, field notes, and reflective journaling. Our preliminary findings include the following themes: refusing to be dismissed and seeking validation, living a hidden life, transitions to long-term coping, and desiring systemic change. Parents of children with FC often feel they are lacking key information and support to effectively care for their child's health. Parents merit increased attention of clinicians and researchers, including efforts to develop reliable, relevant, and accessible resources for families living with this difficult condition.

### **How Can We Use Photography in Mental Health Research?**

Gabriela Trombetta Santos, *Federal University of São Carlos*

Maria de Jesus Dutra dos Reis, *Federal University of São Carlos*

Livia Scienza, *Federal University of São Carlos*

Methods using production of photographs have been explored as alternative instruments of research and psychological intervention. However, there is still little consensus in their designations and procedures. In this context, this work presents an integrative review aimed at investigating the use of photographic methods in the field of mental health over the last 20 years. The research was conducted on LILACS, PsycNET, PubMed, SciELO, and Web of Science databases. Forty-nine articles were accepted and 457 were rejected. Four methods were identified: PhotoVoice, Photo-instrument, Autophotography, and Photo-elicitation. As potential aspects, the use of photography means exploring and sharing personal experiences, assisting health professionals, and creating empowerment. As challenge aspects, the recent feature of photographic methods used in the field of mental health was highlighted, counting on the prevalence of small and nongenerable samples, multiple data analysis methodologies, and inappropriate uses of designations regarding the procedures that were performed.

### **Patient Perspective on New Potential Therapy for Inflammatory Bowel Disease**

Jens Vent-Schmidt, *University of British Columbia*

Theodore S. Steiner, *University of British Columbia*

Canada has the highest prevalence and incidence of inflammatory bowel disease (IBD) globally. Current therapies have many side effects and control symptoms rather than cure the

disease. Our research group developed a potential therapy which involves chimeric antigen receptors, a novel technology pioneered in cancer. The risk associated with this therapy is the same associated with current standard of care therapies in IBD. However, the treatment is conceptually and logistically complex, which might increase perceived risk. Before continuing therapy development, it was important to understand the willingness and perspective of people living with IBD to accept this therapy. We designed and provided educational materials on this therapy, followed by an assessment via an online exploratory survey. We asked participants to rate their willingness to undergo treatment at varying degrees of efficacy. To develop the survey, we conducted iterative focus groups and asked focus group participants to test the final version of the survey. A total of 594 participants completed the survey. Most resided in North America, received at least some college education, and were between 30 and 59 years old. Surprisingly, the vast majority (95%) indicated willingness to try this new therapy if it was shown to be safe and effective. Furthermore, 85% indicated they would consider enrolling in a phase 2/3 clinical trial. Open-ended follow-up questions gave us insights into the decision-making process of survey participants. Furthermore, we learned common fears associated with this therapy. This project laid the foundation for ongoing patient involvement during therapy development.

### **Caregiver Perspectives and Enabling Caregiver Engagement for Bubble CPAP**

Marianne Vidler, *University of British Columbia*

Sangwani Salimu, *College of Medicine, IMCHA Project*

Alinane Linda Nyondo-Mipando, *College of Medicine, IMCHA Project/Department of Health Systems and Policy, School of Public Health and Family Medicine, College of Medicine, University of Malawi*

Severe respiratory distress is a leading cause of mortality among neonates in Malawi. In spite of evidence on the safety, cost effectiveness, and efficacy of bubble continuous positive airway pressure (CPAP) in managing the condition, little is known about the perspectives of mothers and guardians with babies on bubble CPAP. This was a descriptive qualitative study employing secondary analysis of 46 health care workers' in-depth interviews to understand barriers and facilitators to implementing bubble CPAP at a tertiary hospital and three district hospitals in Southern Malawi. We thematically analysed caregiver perspectives as reported by health care workers in Nvivo Version 10 (QSR International). Emerging issues included caregiver fears around the bubble CPAP machine as potentially harmful to their newborns and how inadequate or no information provided to caregivers exacerbated knowledge gaps and was associated with refusal of care. However, good communication between health care providers and caregivers was associated with acceptance of care. Caregivers' decision

making was also influenced by significant others like relatives, and peers advocates were helpful in supporting caregivers and alleviating fears or misconceptions about the intervention. Caregivers need both support from relatives, peers, and health workers and accurate, up-to-date, contextualised comprehensible information from health workers to deal with their fear and anxieties in accepting bubble CPAP for their neonates.

### **Development of a Protocol to Determine Interview Saturation**

Colin Whaley, *School of Pharmacy, University of Waterloo*

Kelly Grindrod, *School of Pharmacy, University of Waterloo*

To ensure that analyses are drawing upon the diverse experiences within a population, researchers strive to reach saturation in qualitative research. While valuable, this is a difficult concept to operationalize. Lowe and colleagues developed a quantitative model to estimate the percentage saturation when using a coding-based qualitative analysis by considering the number of codes observed in the first few interviews coded. The model allows researchers to determine either the percentage saturation of a set of interviews given the total number of interviews coded or to ascertain the number of interviews that need to be coded to reach a given saturation. The purpose of this model is not to provide a target number of new codes to "find" after analyzing a set of interviews but to provide an estimate of how many codes could be expected given the rate of observing new codes in a subset of interviews. In order to develop a protocol for the use of this model, we used it to determine the percentage saturation for a set of 20 interviews to substantiate our claims to the analysis' credibility and dependability. The aim of the analysis was to understand prescribers' views on adding indications to prescriptions and medication labels. This model allowed the research team to determine the percent saturation achieved within our data set and is presented here as a novel method for use in conjunction with traditional qualitative analysis techniques such as thematic analysis.

### **Growth in the Face of Unrelenting Pressure: A Narrative Review of Sibling Donor Experiences in Pediatric Hematopoietic Stem Cell Transplant**

Andrea Winther Klippenstein, *Rady Faculty of Health Sciences, University of Manitoba*

Christina H. West, *College of Nursing, Rady Faculty of Health Sciences, University of Manitoba*

Pediatric hematopoietic stem cell transplant (HSCT) is an intensive, potentially life-threatening treatment increasingly used in child health. There are significant and often overlooked

psychosocial risks during HSCT, particularly for sibling donors. Further, there is a paucity of research about the potential positive gains for siblings who undergo hematopoietic stem cell donation (HSCD), such as the possibility of post-traumatic growth, which refers to positive psychological change or growth despite exposure to traumatic life experiences. We conducted a narrative review, in which we synthesized the literature and identified themes related to trauma and post-traumatic growth experiences of pediatric sibling donors during HSCD. Sibling donors reported diverse experiences of trauma across the HSCT trajectory. Within the review, we identified two main categories related to siblings' experiences of trauma: (1) an overwhelming, unrelenting pressure to donate and (2) experiences of loneliness and isolation, particularly as the family focus intensified on the ill child postdonation. Siblings simultaneously identified the following domains of posttraumatic growth: (1) a deepened appreciation for life and changed priorities, (2) more intimate relationships with others, and (3) increased personal strength. This review highlighted the critical need for a more comprehensive exploration of sibling donors' experiences during HSCT. Qualitative, expressive arts-based research methodologies are highly appropriate and represent a developmentally sensitive approach for future research. Within my doctoral research (AK), I will adopt this methodological approach and will integrate a strength-based framework and digital storytelling, a specific arts-based method, to explore siblings' trauma and post-traumatic growth experiences in the context of HSCD.

### **Learning From Navigation Programs in Chronic Conditions: Reviewing the Literature to Identify Practices to Build Navigation Programs for Individuals With Neurodevelopmental Disabilities and Their Families**

Roslynn Zulla, *University of Alberta*

David Nicholas, *University of Calgary*

Sandy Litman, *Glenrose Rehabilitation Hospital*

Navigation programs have been increasingly used as a strategy to assist individuals and their families search for and access services. Designing navigation programs for individuals with neurodevelopmental disabilities (NDD) and their families requires learning from programs that integrate different services and sectors, offer support to the individual client and their family, address health and health-related needs, and engage a variety of stakeholders in different activities (e.g., implementation and evaluation of the program). Using a participatory action research approach, the team identified eight principles to guide the development of navigation programs for the NDD population and their families. Next, a scoping review methodology was used to identify navigation programs that met this criteria; 2,045 peer-reviewed studies were retrieved from three

databases. From this, 58 navigation programs were identified following three rounds of screening and review. Of the 58 navigation programs, only a small number of programs met all eight principles. Characteristics of these programs included the following: (i) building partnerships across different community stakeholders to collectively address multiple needs (e.g., health, psychosocial care, transportation, funding) that impact individuals and their families, (ii) engaging a variety of stakeholders throughout multiple stages of building the navigation program (e.g., development, implementation, evaluation, and sustainability), and (iii) using a team approach to provide support to individual clients and their families. Implications of these findings emphasize the need to build navigation programs by using a collaborative, community-based and systems approach. Guidelines from this work for navigation system/program design will be offered.

## **Symposia**

### **Symposium I**

#### **Creative Approaches to KT: Translating Narrative Findings of Death and Dying**

Marcy Antonio, *University of Victoria*

In this symposium, we will share (a) the challenges faced when working with dyads and the sensitive topic of death and dying in narrative inquiry; (b) the experiences with two forms of video production; and (c) the lessons learned from a range of creative, arts-based, and digital knowledge translation approaches. We draw from two consecutive narrative inquiries in which we explored the uncertainty of living with life-limiting chronic illnesses (advanced cancer, chronic obstructive pulmonary disease, end-stage kidney disease, heart failure, and HIV). In the first study, we explored patient perspectives of living with a fatal chronic condition and expanded in the second study to include the uncertainties of living-and-dying with dyads of patients and family caregivers. The two longitudinal studies involved 32 and 83 participants (32 dyads), respectively. We sought depth and richness by interviewing participants multiple times over 1–3 years. Our knowledge dissemination strategies were varied and creative in nature.

#### **Abstract I: Arts-Based, Performative KT With Sensitive Topics**

Anne Bruce, *University of Victoria*

Kara Schick-Makaroff, *University of Alberta*

Anita Molzahn, *University of Alberta*

Through this presentation, we will discuss how we focused knowledge translation (KT) strategies towards specific

audiences through performance presentations, art exhibits, found poetry, and booklets. These included patients and families, policy makers, educators, students, and practitioners. In using creative approaches to address the sensitive topic of death and dying, there were potential pitfalls and unforeseen outcomes. Since we did not always know our audiences' background and experiences, our team was attentive to how the KT activities would be received and (mis)understood. Some clinicians voiced apprehension about sharing resources about death and dying with patients that may be too direct or too explicit. These unexpected responses opened opportunities for further analysis and KT development. An additional challenge arose with family and caregiver data collection (conducted separately) that impacted KT. Our second narrative study included family member (dyadic) interviews, where people living with a chronic illness and their family member were asked to share experiences of uncertainty through photographs. Although we aimed to keep these images separate and confidential, the dyads often shared their images with each other. However, during separate individual interviews, participants often shared stories about the images that were private, including experiences they may not have shared with their dyadic partner. This posed ethical and methodological challenges when linking images

### **Abstract 2: Expanding Access and Audience Through Digital and Video Production**

Laurene Shields, *University of Victoria*

Marcy Antonio, *University of Victoria*

Kara Schick-Makaroff, *University of Alberta*

In Canada, the knowledge translation (KT) process is most commonly described in terms of the Knowledge to Action Framework developed by Graham et al. The framework outlines a stepwise process for knowledge synthesis, but this does not necessarily reflect our experience with narrative KT. Through this presentation, we will introduce two different approaches we used in developing videos for knowledge mobilization and how these activities were part of our emergent qualitative design. We will discuss how our process for creating videos integrated back into our narrative analytic approach and the key decisions we made during video production. In our first study, video production followed a documentary format, where individual participants were contacted after formal data collection to see if they would like their stories shared through an audio recording. The videos represented participants' actual voices and incorporated professionally taken photographs that were connected to what participants had shared. The second format involved developing a script from key messages the team identified within our narrative data. The script brought together multiple participants' experiences, relied on editing by the video production team to create continuity and interest, and was communicated by professional actors. Through video excerpts, we will

demonstrate how selecting videos as a KT activity requires consideration of the implications of (a) working with a production team, (b) embodying participants' words through their own voice or with actors, (c) adhering to current preferences for short video segments, (d) representing the multi-layered aspects of people's lives, and (e) integrating analysis within the knowledge synthesis process.

### **Abstract 3: Lessons Learned: Practical Strategies for Creative KT Activities**

Marcy Antonio, *University of Victoria*

Kara Schick-Makaroff, *University of Alberta*

Robyn Wiebe, *University of Victoria*

Although creative dissemination of qualitative findings is laudable, the process and complexity of these strategies raise important considerations. Negotiating how to integrate what is expected from digital and artistic productions versus research findings is a key consideration. We will explore analytic, creative, and institutional differences we have encountered in generating KT that evocatively engage an audience, honour participants' narratives, and adhere to university/ethics/funding requirements. We will discuss how we worked with media consultants and art curators in addressing the tension between staying close to the data and providing "creative license" to maximize artistic impact. This was most poignant when the deeply personal photos that participants shared that were so critical to our analysis were found not to provide the "quality" required for digital media. The development of our web site was also not straightforward; the institutional requirements for fitting with "the brand" lead us to search for other online formats where we would have more flexibility as to how we could present our data. Additionally, with a restricted time frame imposed by funding agency requirements, we found ourselves juggling the demands of in-depth analysis with KT activities. Through this presentation, we describe these and other examples of how to plan for creative KT activities, budget for a range of resource-intense approaches, work with art curators, or media consultants, and ways of matching data with different KT forms.

## **Symposium 2**

### **Research-Based Theatre in Health: Exploring Possibilities and Navigating Challenges**

Susan Cox, *University of British Columbia*

Research-based theatre (RBT) is an emerging methodology that integrates theatre and research. RBT is particularly beneficial in conducting health research and in doing knowledge translation because it allows participants to experience health from different perspectives and to connect individual actions to larger systemic issues. RBT in health also creates novel



opportunities for collaboration between researchers, clinicians, patients, and artists. To be effective, RBT requires stakeholders to work collaboratively and in ways that balance methodological and ethical rigour with the aesthetics that theatre requires. This symposium will explore the possibilities and challenges in using RBT within a health research context. This symposium will provide the audience with a foundation in RBT and deepen their understanding of how to identify and navigate methodological and ethical tensions inherent in this work.

### **Abstract 1: Mapping Impacts, Identifying Gaps, and Charting Opportunities for Research-Based Theatre in Health**

Jennica Nichols, *University of British Columbia*

Research-based theatre (RBT) can be used to conduct primary research as well as to transform existing research into scripted dramatization for knowledge translation. By combining research with theatre, RBT engages the audience both cognitively and affectively. It can therefore increase awareness and knowledge of a health issue while also evoking emotional responses and encouraging reflection. RBT also expands the notion of knowledge beyond what is commonly assumed within knowledge translation (i.e., knowledge as scientific evidence) to include lived experience. This is critical as it enables the audience to see the complexity and context in which health occurs. For example, characters on stage can show the audience how the broader social determinants of health impact individuals or how the health system shapes healthcare providers' practice. RBT can thus show new perspectives and increase understanding across stakeholders. RBT is highly accessible to diverse stakeholders with different educational backgrounds and professional experiences. It therefore can be used to effectively engage patients, families, clinicians, and researchers in new forms of collaboration. Despite its potential, RBT is still in its infancy in health research. This presentation will share findings from a scoping review exploring RBT in health to illustrate achieved impacts and current gaps as well as identify new opportunities. We will also share some ways that the University of British Columbia's RBT Collaborative is working to address these gaps.

### **Abstract 2: Graduate Supervisory Relationships and Well-being: A Case Study in Research-Based Theatre**

Susan Cox, *University of British Columbia*

Michael Lee, *University of British Columbia*

Simangele Mabana, *University of British Columbia*

Research-based theatre (RBT) offers an innovative method of knowledge sharing that uses embodied approaches to catalyze dialogue about difficult or controversial topics. When

audiences experience a performance together, they can discuss sensitive issues in light of the shared experience, commenting on characters and situations rather than their own personal stories. Using RBT, we are developing dramatized scenes about the challenges inherent to graduate supervisory relationships and the impact these relationships have for graduate students' well-being. These scenes will be performed by trained actors for audiences comprised of graduate students, faculty supervisors, administrators, and staff with the purpose of creating a safe space for dialogue about steps that can be taken to support supervisory relationships and improve graduate students' well-being. Throughout this project, we apply an appreciative inquiry lens to emphasize successful as well as problematic supervisory relationships and their implications for graduate student well-being. This presentation will describe the development and piloting processes of this project. It will also include live reading of a scene from the performance and engage session participants in facilitated dialogue. Participation will increase awareness of the challenges inherent to graduate supervisory relationships, identify graduate supervision as a pedagogy, and provide attendees with an opportunity to discuss how RBT enables a collaborative and creative approach to addressing these challenges.

### **Abstract 3: Identifying and Navigating Ethical Tensions in Research-Based Theatre**

Marilys Guillemin, *University of Melbourne*

Jennica Nichols, *University of British Columbia*

Susan Cox, *University of British Columbia*

For most researchers and health care professionals, ethics is well understood; however, this is less so with RBT. We propose three types of ethics that are relevant to RBT. Firstly, RBT includes professional and artistic ethics; this is the ethics that you bring to the practice of theatre and your theatrical artistry. A second type of ethics relevant to RBT is institutional research ethics, that is, the norms and principles that govern all research that involves human participants. The third kind of ethics is everyday ethics. This includes the day-to-day ethical issues that arise when doing an RBT project and that are often not foreseeable or easily defined in terms of institutional ethics or professional ethics. Significant ethical tensions can arise in an RBT project. We will explore some of these tensions and present a set of ethical guideposts designed to guide RBT practitioners through all stages of the RBT development and production process. Like signs on a highway, the guideposts do not tell you where to go but rather make it obvious that a decision is approaching and needs explicit consideration. The ethical guideposts we present were developed through a thematic analysis of written reflections by researchers and artists around their past RBT projects (19 respondents) along with five roundtable discussions with researchers and artists at the University of British Columbia. This presentation will share the results of this 2-year project.

## Symposium 3

### From Knowledge to Action: Using Art and Technology to Translate Knowledge in Qualitative Health Research

Tal Jarus, *University of British Columbia*

Despite the vital contribution of qualitative studies in health, knowledge users usually rely on quantitative findings to support decision making. How can qualitative findings in health become more influential? Within this symposium, we will present ways to translate knowledge to impact decision makers and communicate with stakeholders in meaningful ways. The first presentation will introduce the SocialTech ASD initiative to promote knowledge on ways that children with autism can benefit from the use of technology. The second presentation will include a research-based theatre performance, “Alone in the Ring,” based on the lived experiences of people with disabilities in healthcare professions. The third presentation will present the Inclusive Space project, where KT actions were aimed at creating an advocacy network for inclusion of people with disabilities in healthcare professions. Throughout the symposium, we will discuss the methodology and evaluation aspects as well as the ethical issues of translating knowledge in qualitative health research.

#### Abstract 1: SocialTech ASD Knowledge Translation (KT) Initiative: Parents’ and Clinicians’ Perspectives on Using Technology to Promote Social Skills of Children With Autism

Yael Mayer, *University of British Columbia*

Tal Jarus, *University of British Columbia*

Parisa Ghanouni, *The University of British Columbia; Dalhousie University*

Ally Malinowski, *University of British Columbia*

It has been widely reported that many children with autism spectrum disorder (ASD) have an affinity for computers and video games. This affinity can be a benefit since technology can support the development of life and social skills of children with autism. However, finding organized systematic knowledge of useful technology to promote life and social skills of children with autism is hard. In this article, we will present a KT initiative named SocialTech ASD to promote parents, clinicians, and general public knowledge on ways that children with ASD can benefit from the use of technology. Using the knowledge to action process framework, we created KT materials aimed at enhancing the knowledge of stakeholders on this topic. To evaluate the impact of our KT strategy, we used a mixed-methods approach, including surveys and focus groups

and interviews with participants. Within this article, we will present the KT materials and interventions, the methodology used to evaluate its effectiveness, and the findings from this study.

#### Abstract 2: “Alone in the Ring”: Research-Based Theatre as a Knowledge Translation Tool in Qualitative Health Research (a Presentation and a Theatre Performance)

Tal Jarus, *University of British Columbia*

George Belliveau, *University of British Columbia*

Yael Mayer, *University of British Columbia*

Christopher Cook, *University of British Columbia*

To enhance the impact of qualitative health studies, there is a need to translate the knowledge in ways that will be impactful. We suggest the use of research-based theatre (RBT) as a useful methodology to translate qualitative findings in health research. Theatre offers a powerful medium to promote perspective-taking and emotional identification of new information. By dramatizing research data, RBT humanizes findings and inspires change through thoughtful and heartfelt engagement. We explored the use of RBT to facilitate attitudinal change in support of disabled students and clinicians in health professions. We created a play, named “Alone in the Ring,” which shares the lived experience of students and clinicians in health professions who identify as having a disability. The play is based on 150 interviews, and the performance offers a unique approach to translate some of our key findings by bringing to life the humanity that lies at the core of our research. In this presentation, we will describe the RBT methodology and share our research process, which began with a grounded theory analysis of the data followed by creating a play. We will present a scene from the play, the development process, and the methodological and ethical dilemmas in using this methodology.

#### Abstract 3: Inclusive Space: Creating an Advocacy Network to Implement Qualitative Findings in Health Research

Yael Mayer, *University of British Columbia*

Tal Jarus, *University of British Columbia*

Laura Bulk, *University of British Columbia*

George Belliveau, *University of British Columbia*

Community organizers view power as dynamic, not something held exclusively by few. In grassroots theory for social change, it is believed that groups of people can create power by taking mutual action to achieve social change. According to this theoretical framework, advocacy should be focused on working with many to build a community that will work together

towards a mutual goal. We used this framework to impact policies that affect people with disabilities in healthcare professions. Rich data from a qualitative study, where we heard the lived experiences of students and clinicians with disabilities in healthcare professions, led to a knowledge dissemination project, called Inclusive Space. We created KT materials as well as a campaign to reach policy makers (such as regulators, programs developers, and governmental agencies) and the general public. According to the “nothing about us without us” movement, no social and policy change should be advanced without the full and direct participation of members of the group affected by that change. Therefore, our network included disabled healthcare students and clinicians with the lived experience. Within this presentation, we will present the Inclusive Space Campaign and the building process of the advocacy network.

## Symposium 4

### **How Do We Know that We Are Ethical Practitioners in the Mental Health Field? Lessons From a Cross-Methodological and Interdisciplinary Dialogue**

Mihaela Launeanu, *Trinity Western University*

Although it represents a central concern in mental health practice, the experience of being ethical and the embodied processes underlying it have not been fully elucidated. Through interdisciplinary dialogue and complementary methodological lens, this symposium will highlight some key features of being ethical as a fundamental stance of care in mental health practice. The first paper will introduce the phenomenon of being ethical in the field of mental health nursing and will discuss the basic social processes of ethical action from the vantage point of grounded theory as a methodological framework. The second paper will elaborate the understanding of being ethical in counselling psychology and will discuss the lived experience of being ethical emerging from phenomenological research. The third paper will draw methodological complementarities between phenomenological exploration and Grounded Theory investigation with the purpose of emphasizing how cross-methodological dialogue enriches our understanding of being ethical, with direct consequences for clinical praxis.

### **Abstract 1: Risking Vulnerability: Enacting Moral Agency in the Is/Ought Gap**

Lynn Musto, *Trinity Western University*

The definition of moral distress (MD) was put forward 35 years ago to explain the distress nurses felt when they experienced moral compromise. Making a moral judgment, enacting moral agency, and having constraints on agency have been identified as central to the experience. The enactment of moral agency

and constraints on agency are linked together in the experience. Constraints have been identified as being internal to the health care professional (HCP), or external to the HCP, and rooted in the context in which HCPs work. However, constraints on agency may also be viewed as dynamic, and gaining clarity on MD requires exploring the experience at the intersection of structure and agency. I engaged in this study to explore how HCPs navigated ethically challenging situations in complex acute mental health settings. I conducted this research using grounded theory (GT) methodology in order to focus on the processes participants engaged in when they confronted ethical challenges. The basic social problem participants attempted to negotiate was systemic inhumanity, or the inability of the health care system to consistently extend respect, compassion, and dignity to individuals struggling with mental health issues. The resulting model, *Risking Vulnerability: Enacting Moral Agency in the Is/Ought Gap*, explains how participants were able to act as moral agents in the particular context they were embedded in.

### **Abstract 2: The Lived Experience of Being Ethical: A Phenomenological Understanding**

Ryan Schutt, *Trinity Western University*

What is like to be ethical? Being an ethical person is often thought of as doing the “right thing,” considering all the possible risks and outcomes, thinking rationally to reach the right decision, suppressing our feelings about the given situation, or following the directives of an authoritative document, institution, or person. While these may be important features of living in a world marked by ethical conundrums and uncertainties, I wager that there are other aspects of being ethical that are essential to our ability to enact meaningful, ethical care. I will share findings from a hermeneutic phenomenological inquiry into clinical counsellors’ experiences of being ethical in morally and/or ethically challenging situations that they encountered in their clinical work. Specifically, I will discuss how the presence of attention, the experience of vulnerability in taking an ethical position, the influence of third parties, and proximity and relationship in our ethical reflection and action may come to light in the experience of being ethical. Insights for clinical practice and education will also be shared.

### **Abstract 3: Enriching Our Understanding of Being Ethical: A Cross-Methodological, Interdisciplinary Dialogue**

Mihaela Launeanu, *Trinity Western University*

Being ethical ought to be a foundational exigency in mental health care across disciplines. However, beyond this imperative, several questions still remain and may even haunt us in our darkest hour of moral struggle: “Are we indeed ethical practitioners? If yes, how do we know this? What is being ethical?” Since we can be easily caught in the is/ought gap, it is vital to

develop some flag posts of understanding of what being ethical means so that we could orient ourselves ethically. This article offers the unique opportunity to reflect on our embodied experience and enacting of being ethical in mental health practice at the confluence of a rich interdisciplinary, cross-methodological dialogue. Some of the main questions that will be addressed are: How can we integrate the embodied lived experience of being ethical (e.g., vulnerability and exposure, the presence of the “thirds”) with the ethically imbued action of navigating systemic inhumanity as an enacted way of being ethical? How can experience and action come together in and through embodied ethical agency and action? Since the lived experience of being ethical is a process of becoming, how can the social processes of enacting moral agency shape this experience and the phenomenon of being ethical? Last but not least, the article will highlight the methodological complementarity between grounded theory and phenomenology with respect to enriching our understanding of being ethical in mental health contexts, as well as the practical implications of this understanding.

## Symposium 5

### **The Ethics and Aesthetics of Attunement: Cocreating Creative Expression With People Living With Dementia**

Gloria Puurveen, *University of British Columbia*

Over the past several decades, there has been an increasing attention to the use of the arts with people living with dementia—be it art as a therapeutic intervention, leisure activity, or a mode of research inquiry to understand people’s lived experience. Research, however, has focused more on a range of biopsychosocial–spiritual outcomes than to the processes involved and what might be happening in these various contexts. The three papers in this symposium pay particular attention to the relational contexts in which art-making occurs. Grounded in the notion of ethics and aesthetics of attunement we suggest that at the core of cocreation lies a radical listening that bears witness to the expressions of those with dementia in whatever form it is offered. In “bringing into harmony,” the cocreative act is an invitation to listen beyond the boundaries of self and others and in so doing, promotes interconnection, congruence, and capability.

### **Abstract 1: The Zeitgeist Project: Cocreating Meaningful Stories**

Mariko Sakamoto, *University of British Columbia*

Alison Phinney, *University of British Columbia*

Paulina Malcolm, *University of British Columbia*

As human beings, we all have our own narrative identity, in terms of the stories we tell about ourselves to one another.

While people living with dementia can have challenges in communicating with others, they are still individuals with stories that define them. As such, this presentation is concerned with the Zeitgeist Project, a unique exercise in storytelling, where communication design students and residents living in care homes engage with one another over a series of six sessions, with the goal of cocreating publications featuring the residents’ life stories. These publications are colourful booklets illustrated by the students with thoughtful drawings and pictures and effectively become physical manifestations of the stories the residents share with the students. The Zeitgeist Project has been found to positively impact both the students and residents, particularly in how it has provided a platform for meaningful social interaction and intergenerational exchange. Importantly, Zeitgeist has enabled people of different backgrounds, ages, and abilities to connect relationally, a process that is facilitated by the mutual and shared space that is created by the students and residents as they engage in storytelling. For residents living with dementia, it is within this storytelling space, where the students strive to stay attuned and responsive to the residents’ narrative arcs, that their stories come to the fore. In this way, the Zeitgeist project is particularly effective at demonstrating that people living with dementia still have a sense of self and identity to share and as such, their own stories to tell.

### **Abstract 2: The Resonance of Relational Attunement in Music Therapy: A Case Study**

Gloria Puurveen, *University of British Columbia*

Susan Summers, *Capilano University*

Alison Phinney, *University of British Columbia*

There is a growing understanding of the efficacy of music therapy in dementia care, with evidence pointing towards outcomes related to improved quality of life and overall functioning and reduced incidents of responsive behaviours. While research across multiple disciplines demonstrates these outcomes, much less is known about what is going on in practice that contributes to impactful interventions. As part of a larger mixed-methods intervention study examining the impact of music therapy in dementia, we present a single case study to unpack how music therapy works with an individual with dementia. Data are derived from 3 hr of video recordings of music therapy sessions conducted with a woman with advanced dementia and 8 hr of video-reflexive interviews with the certified music therapist. Interpretive analysis demonstrates three intersecting themes reflecting the cocreation of the therapeutic-musical space, which lies at the heart of such interventions. This space is characterised by deep and responsive listening fueling the music therapist’s intentional use of musical elements and their own therapeutic self to cocreate (1) an anchored space that contributes to a sense of safety and security; (2) an improvisational space that promotes exploration, play, and possibility; and, (3) a dialogical space that taps into the strengths of the individual with dementia.

and what she brings to the relationship in the moment. These results have significant implications on how music therapy is practiced with individuals with dementia and the need for careful attention to ethics and aesthetics of attunement in the therapeutic relationship.

### **Abstract 3: Methodological Reflections on Art-Elicitation Workshops With People Living With Dementia and Their Care Partners**

Gloria Puurveen, *University of British Columbia*

Susan Cox, *University of British Columbia*

Natasha Damiano, *University of British Columbia*

The creative participation in research of people living with dementia and their care partners whether through poetry, performance, storytelling, or the visual arts has contributed significantly to our understanding of the lived experience of dementia. From a methodological perspective, however, there is a need to more fully understand the processes involved in

using the arts in research with people with dementia. As part of a larger study, we conducted arts-elicitation workshops with individuals living with dementia and their care partners with the purpose of exploring what participants would like others in their communities to know about living well with dementia to the end of life. Data for this presentation comprise observational field notes, photographs, and video from two workshops and follow-up interviews with 10 workshop participants. Interweaving the notions of ethics, aesthetics, and attunement, we suggest that cocreation and creative expression rests in the careful consideration of (1) the fluidity of artistic practice and the dynamic relational context in which cocreation is situated; (2) the imaginative creative risk-taking inherent in creating art, whilst attuning to feelings of uncertainty and internal judgments of what might constitute “good” art; and (3) the building of personal and collective meaning through the making, sharing, and receiving of art. We discuss methodological implications of these findings, both for how creative participation in research of people living with dementia might be further developed, and in light of the kinds of claims that might be made about the understandings of their lived experience generated through artistic practice.